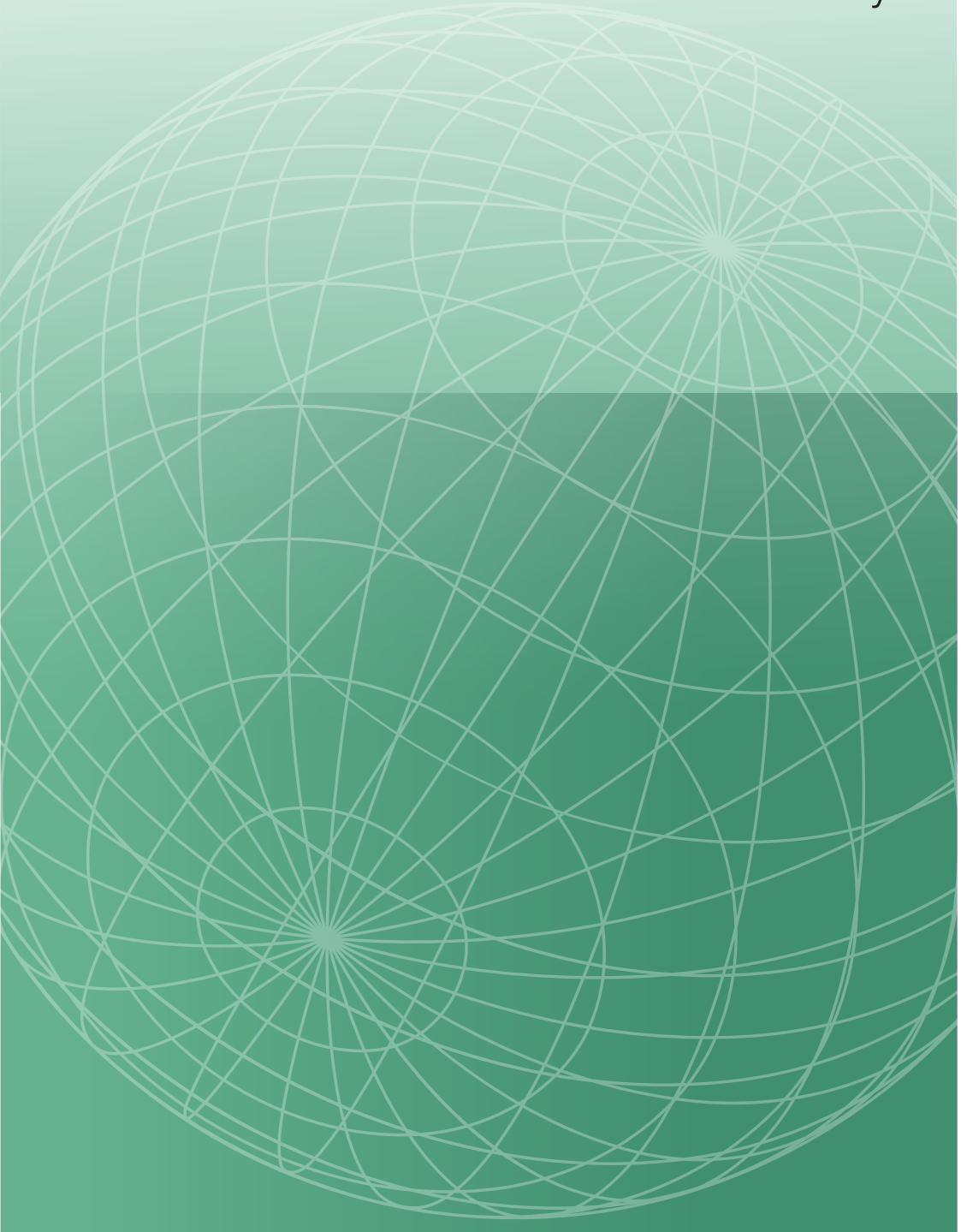
Best practice guidelines for professional carers in emergency seizure medication

Training standards for the safe administration of buccal (oromucosal) midazolam in the community



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Contents

Authorship and acknowledgements

This document is the third edition of the best practice guidelines for professional carers on administering emergency seizure medication. It builds on and replaces previous editions of the guidelines published by the Epilepsy Specialist Nurses Association (ESNA) in 2019 and 2023, which focused on training professional carers in the safe administration of buccal (oromucosal) midazolam for treating prolonged or cluster seizures in community settings.

These latest guidelines were developed under ESNA's leadership and reflect collaboration between clinicians, educators, researchers and charitable organisations from across the UK and Ireland. A full list of contributors and their biographical summaries can be found in Appendix VI: Contributors and acknowledgements.

Review lead and lead authors

- Caryn Jory – Lead Epilepsy Specialist Nurse and Vice Chair, ESNA
- Deborah Coker – Lead Epilepsy Specialist Nurse and Secretary, ESNA
- Sally-Ann Remnant – Clinical Nurse Specialist in Epilepsy Adults, Executive Member ESNA
- Fiona Short – Roald Dahl, Epilepsy Specialist Nurse for Complex Epilepsy and Transition, Executive Member ESNA

Core Best Practice Revision Group

- Shelley Anderton – Epilepsy Specialist Nurse Lead (Adults)
- Jo Campbell – Roald Dahl Children's Epilepsy Nurse Specialist
- Elaine Cowan – Practice Development Nurse, William Quarrier Scottish Epilepsy Centre
- Edel Curran – Training and Quality Manager, Epilepsy Ireland
- Alan Foster – Managing Director, Essential 6 Ltd
- Alison Fuller – Director for Health Improvement and Influencing, Epilepsy Action
- Pollyanna Kellett – Lecturer in Adult Nursing
- Fiona Kettell – Operations Manager, Epilepsy Wales
- Michael Loizou – Associate Professor and Co-Director, Centre for Health Technology
- Andree Mayne – Education, Information and Support Services Manager, Epilepsy Society
- Kirsten McHale – Nurse Consultant, Young Epilepsy
- Maisie Meegan – Engagement Coordinator, Epilepsy Action
- Lisa Obrien – Head of Health and Wellbeing, formerly at The Meath Epilepsy Charity
- Simon Privett – Learning and Training Lead, Epilepsy Action

Review Committee (wider consultation group)

Clinical members

Carys Amies • Rebecca Boxall • Christine Cole • Emma Christie • Keri John • Sarah Kerley • Jenny Piedot • Jay Price • Marion Saunders

Education and training specialists

Nicola Fielding • Sarah Gibson • Denise Kindleysides • Samantha Loosley • Nicola Milne • Tara Smith • AJ Stewart

Organisational and technical advisors

Amir Ali • Jonathan Steed

Specialist advisors for paraldehyde guidelines (Appendix VI)

- Matthew Garrod, Lead Neurosciences Pharmacist, University Hospital Southampton NHS Foundation Trust
- Sabrina Tierney Paediatric Pharmacist, Royal Cornwall Hospitals NHS Trust

Expert advisor for midazolam guidelines

- Professor Rohit Shankar MBE, FRCPsych – Professor in Neuropsychiatry, Cornwall Intellectual Equitable Research (CIDER), University of Plymouth, Peninsula School of Medicine

ESNA extends its sincere thanks to all contributors and stakeholders who participated in the consultation, review and consensus-building process.

Foreword

It is a privilege to serve as Expert Advisor to the Epilepsy Specialist Nurses Association (ESNA) for this third edition of the Best practice guidelines for professional carers in emergency seizure medication. These 2026 guidelines represent a significant and timely evolution in our collective efforts to ensure that people with epilepsy receive safe, dignified and equitable care in community settings.

Epilepsy remains one of the most common serious neurological conditions worldwide. For a significant minority of individuals, particularly those at risk of prolonged or cluster seizures, the need for timely administration of rescue medication can mean the difference between recovery and avoidable harm. In the UK, buccal (oromucosal) midazolam is recognised by the National Institute for Health and Care Excellence (NICE) as a first-line treatment for prolonged convulsive seizures in community settings. However, access to medication alone does not confer safety. Safety depends on competence, confidence, governance and accountability.

Over the past decade, we have learned through national audit, research and lived experience that variation in training standards can translate into variation in outcomes. The Rescue Epilepsy Medication and Training (REMIT) study, undertaken in collaboration with the International League Against Epilepsy (ILAE), highlighted inconsistencies in prescribing practice, training quality and carer confidence across regions. These findings reinforce a simple but urgent truth: training must be robust, standardised and evidence informed.

This edition of the guidelines responds directly to that challenge. It strengthens governance by clarifying the shared responsibilities of commissioners, providers, prescribers and trainers. It introduces a tiered trainer competency framework aligned with ESNA's professional standards. It formalises oversight of train-the-trainer programmes under ESNA's stewardship. It defines minimum training duration and assessment standards, embedding reflective practice, risk awareness and sudden unexpected death in epilepsy (SUDEP) education as core components. Above all, it prioritises safety without losing sight of dignity and person-centred care.

Importantly, these guidelines recognise that family and professional carers often carry significant responsibility in high-pressure situations. They deserve training that is not only technically accurate, but also practically relevant, psychologically supportive and reinforced through regular retraining cycles. Competence cannot be assumed; it must be demonstrated, refreshed and supported within a clear governance framework.

From my perspective as a clinician and researcher working at the interface of epilepsy and intellectual disability, I am particularly encouraged by the explicit emphasis on equity. Individuals with intellectual disabilities and complex needs are disproportionately affected by epilepsy-related morbidity and mortality, particularly in receiving rescue medication protocols. Ensuring that emergency seizure medication is administered safely, promptly and appropriately in community environments is therefore not merely a clinical obligation, it is a matter of ensuring protocols are actively reviewed and protected.

These guidelines reflect extensive collaboration between clinicians, educators, pharmacists, voluntary-sector partners and people with lived experience across the UK and Ireland. They embody consensus, transparency and a shared commitment to continual improvement. It is important to note that these guidelines should not be considered static; rather, they provide a national baseline against which innovation, audit and reflective practice can flourish.

In safeguarding the lives and dignity of people with epilepsy, we are reminded that professional responsibility is never abstract; it is profoundly human and shared. As John Donne wrote in Meditation XVII:

"Any man's death diminishes me,
Because I am involved in mankind,
And therefore never send to know for whom the bell tolls;
It tolls for thee."

These lines speak to the collective duty that underpins these guidelines – that in striving for safer, more consistent and more equitable care, we act not only as professionals, but as part of a shared humanity.

I commend this document to commissioners, training providers, regulators, healthcare professionals and carers alike. Its consistent implementation will strengthen safety, reduce unwarranted variation and, most importantly, protect the lives and dignity of people with epilepsy.

Professor Rohit Shankar MBE, FRCPsych
Professor in Neuropsychiatry

Chair of the RCPsych Faculty of Intellectual Disability and the Associate Dean for Academic training

Cornwall Intellectual Disability Equitable Research (CIDER), University of Plymouth
Expert advisor to ESNA midazolam training guidelines 2026

1. Introduction

The safe and effective administration of emergency seizure medication, also referred to as 'rescue medication', for epilepsy in the community is a critical component of care for people at risk of prolonged or cluster seizures. This responsibility, often placed on professional carers and non-clinical staff, demands robust and standardised training to protect patients' safety, uphold their dignity and prevent avoidable harm to them (Shankar et al., 2017).

Epilepsy remains one of the most common neurological conditions worldwide, with status epilepticus (SE) (see Glossary) representing a life-threatening tonic clonic convulsive seizure last for more than five minutes (Trinka et al., 2015). The timely administration of emergency seizure medication, particularly buccal midazolam, is essential to reduce the risks associated with SE, including long-term disability and death. In the UK, buccal midazolam (see Glossary) is widely recognised as the first-line treatment for tonic clonic convulsive seizures in community settings due to its effectiveness and ease of administration. It also offers people with epilepsy more dignity than rectal alternatives (NICE, 2022).

Evidence from ESNA and the International League Against Epilepsy (ILAE) British branch's Rescue Epilepsy Medication and Training (REMIT) study (McBride et al., 2025) highlights the complexities of community-based administration of emergency seizure medication, revealing significant variations in prescribing practices, carer confidence and training delivery across the UK. While most healthcare professionals (HCPs) adhere to NICE or Scottish Intercollegiate Guidelines Network (SIGN) and local practice guidelines, concerns remain about the misuse, overuse or inappropriate reliance on midazolam, particularly in cases involving vulnerable people with learning disabilities. The REMIT study emphasises that safe administration is not simply about having access to the medication, but also about having well-trained, competent carers supported by clear emergency care plans, regular training and systems of clinical oversight (Tittensor et al., 2021).

This position is reinforced by the Care Quality Commission (CQC), which states unequivocally that care staff administering emergency (rescue) medicines must be trained and competent. Staffing requirements are set out clearly in Regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (HM Government, 2014).

Furthermore, LeDeR (Learning from Lives and Deaths – People with a learning disability and autistic people) reports published by Bristol University in 2015 and 2021, and by King's College London (KCL) in 2023, identify epilepsy as a leading, and often preventable, cause of death among people with a learning disability (KCL, 2025). The Step Together report (Shankar et al., 2020) builds on this by highlighting the role of workforce training, clinical competencies and integrated care in improving outcomes. Both the LeDeR and Step Together reports prioritise robust, standardised training for carers as a cornerstone of safe and equitable epilepsy management in the community.

This latest version of the ESNA best practice guidelines aims to provide an updated and evidence-informed framework to support consistent high-quality training for carers across all settings. It reflects evolving clinical standards, lessons from practice and the need to prioritise the safety and dignity of people with epilepsy.

2. Target audience

These guidelines are primarily intended for all stakeholders working with people with epilepsy in the UK. These include:

- HCPs developing and delivering buccal midazolam training courses
- professional health and social care workers supporting people with epilepsy in the community
- HCPs developing and delivering 'train-the-trainer' (TTT) courses (see Glossary)
- commissioners (see Glossary), service providers, voluntary organisations, the CQC in England and similar organisations in Wales, Scotland and Northern Ireland
- people with epilepsy, their families and carers.

3. Overview and key changes from 2023 guidelines

This third edition of the ESNA midazolam training guidelines replaces the 2019 and 2023 versions (ESNA, 2019; 2023a) and is based on the most comprehensive review to date. It updates national best practice standards for professional carers in the safe administration of emergency seizure medication, incorporating current evidence, regulatory expectations and learning from practice.

Key developments

- **Broader scope:** The guidelines now cover emergency seizure medication more widely, retaining buccal midazolam as the core focus but including rectal diazepam and paraldehyde for use in specialist contexts.
- **Clearer structure and purpose:** New sections set out guiding principles and methodology, defining ESNA's national role and the consensus process used to update the guidelines.
- **Stronger governance and accountability:** The guidance includes revised standards for commissioning and delivery that clarify the joint responsibilities of commissioners, providers, trainers and prescribers, with any deviation from standards requiring written justification.
- **Updated trainer competencies:** These are based on a new tiered framework (novice–competent–expert) that aligns with ESNA's three epilepsy nurse competency frameworks. The guidance specifies minimum qualifications (Award in Education and Training (AET) Level 3 or equivalent), peer endorsement and a two-year revalidation cycle.

- **Train-the-trainer (TTT) oversight:** ESNA is formally designated as the professional body responsible for developing, accrediting and monitoring all TTT programmes, ensuring national consistency and quality assurance (QA).
- **Training delivery and duration:** Face-to-face teaching remains the gold standard, with blended learning (see Glossary) or live virtual formats allowed only under defined conditions. Initial courses must last at least six hours and refresher courses at least three hours every two years.
- **Refined course content**: Core modules now include epilepsy awareness, seizure management, sudden unexpected death in epilepsy (SUDEP), risk assessment and midazolam administration, and are supported by optional and specialist modules.
- **Assessment and competence:** The online test has been discontinued due to low take-up and lack of funding, and replaced by multi-method assessment and consistent use of ESNA's Competency checklist for the administration of buccal (oromucosal) midazolam (ESNA, 2022), aimed at carers.
- **Supporting tools:** Appendices to the guidelines have been updated and expanded to include a revised emergency care plan template, a summary for commissioners of the purpose, benefits and requirements of TTT, and details of what the current carer competency checklist covers.
- **Forward view:** This acknowledges that the guidance will need to be revised to incorporate other administration methods of midazolam.

A detailed summary of major changes since the previous edition is provided at Appendix I for reference.

4. Guideline principles

These principles set out the 2026 guidelines' scope, purpose and underpinning standards. The guidelines provide an evidence-informed framework to support safe, consistent and high-quality training in the administration of buccal (oromucosal) midazolam.

This third edition follows the 2019 and 2023 versions and responds to developments in clinical evidence, regulatory expectations and feedback from practice.

The purpose of the guidelines

1. Set national standards for the design, commissioning and delivery of training in the use of emergency seizure medication, with a primary focus on buccal midazolam.
2. Promote consistency across providers and settings, reducing variation and ensuring training is aligned with current clinical and safety requirements.
3. Safeguard people with epilepsy by ensuring carers are competent, confident and supported by clear emergency care plans (see Glossary) and governance structures.
4. Guide commissioners, providers and regulators in assessing training quality and accountability (see Glossary).
5. Ensure inclusivity by recognising the individual roles and responsibilities of both healthcare professionals and trained non-healthcare staff, while embedding appropriate oversight and revalidation.

These standards are drawn from:

- a review of previous editions of the ESNA guidelines and the former Joint Epilepsy Council (JEC) 2002 good practice guidelines on the treatment and care of people with epilepsy, and
- evidence from national studies, including the REMIT study (McBride et al., 2025).

Together, these principles aim to ensure that emergency seizure medication training meets national guidance and regulatory requirements.

The guidelines set national standards to ensure that professional carers are trained, competent and supported in the safe administration of emergency seizure medication, with a primary focus on using buccal midazolam for prolonged or cluster seizures in community settings.

They promote consistency across providers, safeguard people with epilepsy through clear emergency care plans and clinical oversight (see Glossary), and provide commissioners, providers and regulators with a benchmark for assessing training quality.

Above all, they prioritise and protect the equity of care for people with epilepsy in community settings and their safety and dignity.

Guideline principles at a glance
• **National standards:** Set clear expectations for training in emergency seizure medication.
• **Consistency:** Reduce variation across providers and settings.
• **Safety and competence:** Ensure carers are trained, confident and clinically supported.
• **Accountability:** Provide benchmarks for commissioners, providers and regulators.
• **Inclusivity:** Recognise roles of both HCPs and trained non-HCPs, with appropriate oversight.
• **Equity of care:** Prioritise the safety, dignity and rights of people with epilepsy.

5. Methodology (summary)

The 2026 guidelines were developed using an evidence-informed and consensus-based approach that combined a structured literature review, stakeholder consultation and expert peer review under the oversight of the ESNA Executive. This process ensured transparency, rigour and national alignment across clinical and educational standards. A full description of the methodology, including the consultation process and governance arrangements, is provided in Appendix II.

6. Standards for commissioning or delivering buccal midazolam training

The guidelines represent the best practice standards for the commissioning and delivery of buccal midazolam training. Training should adhere fully to the requirements set out in this document.

Where deviation from these standards is proposed, this must:

- be justified by a clear, documented rationale
- identify explicit lines of accountability extending to the trainer, the training provider and, where applicable, the commissioner or prescriber, and
- be agreed with the commissioning body prior to training delivery.

Responsibility for ensuring compliance with these standards rests jointly with the care providers that are requesting training, the person trained to administer buccal midazolam, the training provider and the commissioners of services for people with epilepsy.

Commissioner and provider responsibilities at a glance

- **Commissioners:** They must ensure all the training they contract complies with ESNA best practice standards, and that any proposed deviations are reviewed and documented before training is booked.
- **Variations and deviations from best practice standards:** ESNA recognises that there are situations when variations or deviations from the standard training models are justified. Commissioners and providers must be consulted and any variations agreed and justified.
- **Continuous learning and feedback:** ESNA intends to promote reflection, enable shared learning across services and identify innovative or emerging best practices, while ensuring that unsafe or unmonitored variations are avoided. Oversight and review of such learning will sit within ESNA's governance remit as part of its ongoing role in maintaining and evolving national standards.
- **Training providers:** They must deliver courses in line with these guidelines and provide evidence of trainer competence, governance and insurance cover.
- **Training requests:** Individuals, organisations and services must confirm that the training commissioned meets ESNA standards and is appropriate for the roles of their staff.
- **Prescribers:** They should ensure that emergency care plans and training arrangements align with clinical need and are delivered by trainers who meet the stated competencies.

All parties must clearly record accountability for any deviation from the standards, with a written rationale and agreed oversight arrangements.

7. Trainer competencies

General principles

To promote safety, consistency and inclusivity, epilepsy trainers may come from either healthcare professional (HCP) or non-HCP backgrounds, but only if they meet defined clinical and teaching competencies. A tiered trainer model aligned to the ESNA competency frameworks is recommended. Oversight mechanisms should include regular revalidation and peer review.

Rationale

This reflects the Review Committee's consensus regarding the structured inclusion of non-HCPs, provided competency standards and oversight match those of HCPs. The tiered model ensures clarity of roles, supporting flexibility without compromising safety.

Epilepsy trainers can be categorised as five distinct groups within the tiered model. Table 1 outlines each group and the rationale behind it.

Table 1: Epilepsy trainer groups and category rationale

Group	Governance/ oversight	Trainer type	Minimum requirements	Teaching/ qualification
Group 1 – clinical trainers (HCPs)	Deliver training to individuals/families in care settings	Registered nurse or doctor with ≥1 year's epilepsy care (*novice level)	Peer endorsement by a clinical colleague	Continuing professional development (CPD) in epilepsy care Personal or organisational indemnity insurance

Rationale Maintains alignment with current clinical practice while reinforcing professional accountability. Links directly to the ESNA frameworks' novice level and ensures peer validation rather than managerial sign-off, promoting safety and clinical relevance.				
Group 2 – HCP trainers (external)	Provide training externally across organisations, under governance	≥3 years' epilepsy care (*competent level)	Working towards or holding Adult Education and Training (AET) Level 3 (or equivalent)	Peer or educator endorsement Appropriate insurance required
Rationale Raises the baseline expectation for external training delivery by requiring competent-level clinical expertise and formal or developing teaching qualifications. Encourages ongoing professional development and ensures consistent quality across organisations.				
Group 3 – train-the-trainer (registered HCPs)	Facilitate TTT programmes, mentor trainers and ensure quality assurance (QA)	≥5 years' epilepsy care (*expert level or competent working towards expert)	AET Level 3 (minimum) Under approved awarding body (Ofqual/Scottish Qualifications Authority)	Revalidation every two years QA oversight Accountability to ESNA
Rationale Clarifies qualification standards (minimum AET Level 3 or equivalent) and embeds accountability through recognised awarding bodies, e.g. Ofqual or the Scottish Qualifications Authority (SQA). Supports national consistency, governance and quality assurance across all TTT programmes.				
Group 4a – in-house non-HCP trainers	Deliver internal training only under HCP oversight Deliver to dedicated staff teams in specific settings where the epilepsy needs of the service user are well known to and understood by the trainer	≥3–5 years' epilepsy care (*novice, validated by HCP)	Completion of ESNA-endorsed TTT course	Restricted to own organisation Revalidation every two years Organisational indemnity insurance
Rationale Allows inclusion of experienced non-HCPs under strict safeguards, ensuring novice-level competence validated by HCP trainers. Provides a safe and sustainable model for internal delivery, limited to the trainer's own organisation.				
Group 4b – external non-HCP trainers (pilot)	At present ESNA does not recommend this category of trainers but intends to review and evaluate this option in due course.			
Rationale Included for transparency and future planning. Controlled pilot testing only, due to risks of inconsistent governance or quality assurance in external non-HCP delivery. Evidence-based evaluation required before any national roll-out.				

*Related to ESNA nurse competency frameworks (ESNA, 2023b)

Key points

- All trainers must revalidate every two years and maintain evidence of continuing professional development (CPD).
- Peer endorsement should come from an HCP with recognised epilepsy expertise.
- Non-HCP training must always occur under appropriate clinical oversight.
- Any deviations from this framework must be documented and justified.

Summary of changes to training guidelines

The latest changes:

- introduce a tiered trainer model aligned with the ESNA epilepsy nurse competency frameworks
- define minimum clinical levels (novice, competent, expert) for each group
- replace line manager sign-off with peer clinician endorsement
- set minimum qualification of AET Level 3 (or equivalent) for Group 3 facilitators
- remove separate teaching qualification requirement for Group 4a, which has been incorporated into the TTT course
- mandate the use of ESNA-approved TTT courses for governance and oversight (Group 3 and TTT)
- clarify the scope and safeguards for in-house non-HCP trainers
- flag Group 4b as under development and requiring pilot and further discussion, and
- introduce a two-year revalidation cycle across all trainer levels.

Delivery of training

Summary of the Delphi process

The Delphi process is a structured method used to gather expert consensus through multiple rounds of anonymous feedback (see Glossary). It involves a panel of subject-matter experts who independently review, rate and refine statements or recommendations. After each round, a facilitator summarises the group's responses and shares them with the participants, allowing them to reconsider their views in light of the group's feedback. This iterative process continues until a clear consensus is reached.

In the context of these guidelines, the Delphi process (see Appendix II) was used to determine the most effective and safe modes of delivering epilepsy awareness and midazolam administration training, ensuring that the final recommendations reflect a broad professional agreement supported by evidence and best practice.

The consensus from the Delphi process is that face-to-face training is the optimal mode of delivery for epilepsy awareness and midazolam administration training. However, it is acknowledged that there can be limitations or barriers to this option. Therefore, a hybrid course combining both face-to-face and live virtual training may be acceptable in a limited number of cases.

Acceptable delivery models

- Face-to-face training remains the gold standard, especially for skills-based components like seizure response and buccal midazolam administration.
- Blended learning models may be permitted if:
  - theory is delivered live with real-time interactivity
  - carers have access to physical demonstration materials, and
  - practical skills are validated in person by a qualified trainer.

- Live virtual training may be used only in exceptional circumstances where physical face-to-face delivery is impractical.
- Online-only, pre-recorded training is not acceptable where emergency seizure medication administration is expected.

Rationale
This model preserves safety while acknowledging practical constraints in some locations. It reflects lessons learned during the Covid-19 pandemic and ensures interactive, high-quality training standards are maintained even when face-to-face delivery is not feasible.

Low-risk settings

Training delivery may be adapted in settings where staff are not responsible for administering buccal midazolam or managing seizures directly. This is suitable for general awareness training only.

Examples include:

- school or day-service staff without direct care responsibilities
- ancillary or facilities staff
- colleagues in workplace settings, and
- care homes where no anti-seizure medication is prescribed.

Rationale
This section of the guidelines clarifies where reduced or awareness-only training is appropriate. This prevents misuse of online-only training in higher-risk scenarios and helps tailor training to individual roles while preserving safety and confidence that practice meets regulatory requirements.

8. Duration and structure

Initial epilepsy awareness and buccal midazolam training should last six total learning hours (TLHs) (see Glossary). This includes theoretical instruction, demonstration, supervised practice, reflection and assessment by the learner's line manager using the carer competency checklist (see Appendix IV).

Refresher training (see Glossary) should occur at least once every one to two years and last a minimum of three TLHs. It should include updates on clinical guidance and product information, increase the learner's confidence and understanding, and prepare them for competency reviews undertaken by their line manager using the carer competency checklist (see Appendix IV).

Each training course should be recorded for continuing professional development (CPD) purposes as six CPD hours for initial completion and three CPD hours for refresher training. These hours contribute to revalidation or annual appraisal requirements for all staff across different organisations.

Prerequisite training

All participants undertaking epilepsy awareness and buccal midazolam administration training must have completed their organisational basic life support (BLS) training within the preceding 12 months. This ensures that learners have the necessary underpinning knowledge and confidence in emergency response, airway management and when and how to call for help (999). Employers should verify learners' BLS certification or ensure that they undertake equivalent training before attending the course.

Rationale

Defining total learning hours (TLHs) improves transparency and supports alignment with nationally recognised education and qualifications frameworks, including Ofqual-regulated qualifications and the Regulated Qualifications Framework (RQF) at Level 3. The inclusion of TLHs and continuing professional development (CPD) equivalence enables recognition of the training as formal professional development and supports consistent recording of staff competence within organisational training and governance systems (Ofqual, 2025).

Although the evidence base does not prescribe exact training duration, both educational and patient safety literature demonstrate that adequate contact time, combined with supervised practice and structured feedback, is associated with improved medication safety and increased practitioner confidence in high-risk clinical tasks (World Health Organization, 2019; General Medical Council, 2015).

The literature similarly does not mandate any fixed training duration in relation to epilepsy and emergency medication training. However, national guidance and educational reviews consistently identify core features required to support safe practice. These include: sufficient facilitated learning time; experiential learning approaches such as simulation or skills rehearsal; timely feedback; and regular refresher training to maintain competence over time (Shankar et al., 2017; NICE, 2022).

On this basis, the guidelines specify a minimum of six TLHs for initial training and three TLHs every two years for refresher training. These minimum standards reflect established educational principles for skills-based learning and medication safety and are proportionate to the operational requirements of healthcare and care-sector training programmes (World Health Organization, 2019).

Epilepsy trainers and organisations may choose to extend the training length – for example, for less experienced staff – but the training should not fall below the minimum standard without recorded justification.

Key principles underpinning course length

- **Alignment with learner outcome objectives:** Sufficient learning hours are required for participants to master recognition of seizures, safe midazolam administration and appropriate escalation.
- **Repetition and feedback:** There are built-in opportunities for supervised practice within the teaching plan to promote long-term retention of knowledge and skills and reduce errors.
- **Adaptation to learner needs:** Trainers can extend duration or add modules for learners with limited experience but should not reduce course length below the minimum TLHs without justification.
- **Continuing professional development:** Refresher sessions should maintain competence, support CQC inspection evidence and provide CPD recognition.
- **Governance and consistency:** Defining TLHs will help commissioners, employers and regulators verify that staff have undertaken a recognised level of study.

These standards therefore provide a consistent national baseline for both clinical safety and workforce development while preserving flexibility for service-specific adaptation.

Recommended group size

It is recommended that training groups consist ideally of 4–16 participants and should not exceed 16 participants.

There is no single universal rule regarding group sizes for learning in the medical field. However, small groups of 4–16 learners can optimise interactions, safety and educational value, and provide supportive learning environments. Students in larger groups are less likely to offer opinions and ask questions, and may feel excluded from discussions and debates, leading to lower educational, safety and learning value (Ofei-Dodoo et al., 2018; Mackey et al., 2025; Nabecker et al., 2021).

Rationale

There is growing evidence that small group teaching provides a 'fruitful' learning environment, maximising learning potential, especially in healthcare settings (Burgess et al.,2020).

Small groups are seen as essential because they support active learning, individual feedback, clinical reasoning development and safe practice discussions – all central to preparing healthcare learners for real-world clinical environments (Ofei-Dodoo et al., 2018; Mackey et al., 2025; Nabecker et al., 2021).

Several professional bodies support small group learning, including:

- the Health and Care Professions (H&CP) Education Leads Group, National Association of Educators in Practice (NAEP) and the Council of Deans of Health (CoDH) in their practice education guidance, which states that learners should have an inclusive, learning-centred, empowering experience (BDA, 2016)
- the Health and Care Professions Council (HCPC), which promotes safe and effective training, via small groups that support supervision, reflection and applied learning, in its standards of education and training (HCPC, 2017), and
- the General Medical Council (GMC) in Promoting excellence: standards for medical education and training, which emphasises supervised, interactive, practice-based learning (GMC, 2015).

Their guidance features core elements of:

- interactive feedback
- supervision
- reflection
- practice-based learning, and
- inclusivity and being learner-centred.

Use of pre-course materials is recommended to optimise contact time and enhance learner engagement during face-to-face or blended training. Materials should be well-crafted, interactive and reflective, helping learners to connect theory to practice before attending the session.

Suggested pre-course resources may include:

- a short, narrated video or digital handout introducing key principles of epilepsy, seizure management and emergency seizure medication use
- a brief current article, policy update or guidance summary relevant to community seizure care, and
- a short case study or scenario designed to encourage problem-solving and self-reflection.

The total estimated pre-course study time should be about one hour, structured so it can be completed in short, manageable segments. This provides sufficient preparation without creating an undue burden for participants with work or family commitments.

Learners should be encouraged to identify any areas where they would benefit from further independent study or revision. For registered professionals, such reflection and self-directed learning can be recorded as part of Nursing and Midwifery Council (NMC) revalidation or equivalent CPD evidence.

Pre-course materials should therefore aim not only to convey information but also to stimulate curiosity, promote self-assessment and prepare participants for active participation and hands-on practice during the course delivery, whether this is in person or online.

Rationale
Pre-course preparation supports the principles of adult learning by allowing participants to build foundational knowledge before attending the live session. This enables more effective use of guided learning hours (GLHs) for interactive discussion, skills practice and feedback. Structured pre-learning encourages active engagement and self-reflection, helping participants link theoretical understanding to real-world care situations (Mayer, 2020). Research across clinical education consistently shows that blended approaches – combining independent preparation with face-to-face teaching – improve knowledge retention, confidence and skills performance in medication administration and emergency care. When aligned with learning outcomes and CPD or revalidation requirements, pre-course materials also contribute to professional accountability and continuing competence (Hew and Lo, 2018).

9. Course components

- Training should be modular in design, ensuring consistent delivery of core requirements while allowing flexibility for additional or specialist topics tailored to learner needs and service contexts.
- Core modules are mandatory for all participants.
- Optional modules (see Glossary) may be included according to different roles or settings.
- Specialist modules (e.g. rectal paraldehyde; see Appendix VI) may be provided only by suitably qualified trainers, and should be included as additions to training courses and supported by clear safety guidance.

The essential components of epilepsy training

Changes and additions to the core modules aim to make learner outcomes explicit, measurable and fully aligned with the ESNA competency framework levels (novice–competent–expert) while reinforcing governance, communication and reflective practice, which are areas increasingly considered in CQC assessments and NICE quality standards and indicators.

Epilepsy awareness

Table 2 sets out individual elements of epilepsy awareness training content and expected learner outcomes.

Table 2: Epilepsy training core content and learner outcomes

Core content	Learner outcomes
What is epilepsy?	Understand the definition of epilepsy and seizures
What causes epilepsy?	Identify common causes of epilepsy
Diagnosis and differential diagnosis	Recognise the process and considerations in diagnosis
Recognising and describing seizures	Describe seizure events in clinically useful detail
	Recognise how to record and communicate seizure descriptions accurately within seizure records and individual care plans
Specifically recognising tonic–clonic seizures	Be able to recognise key features of a tonic–clonic seizure
	Know what action to take if an individual has a tonic–clonic seizure, including first aid, and when to escalate
Triggers for seizures	Identify common seizure triggers

Core content	Learner outcomes
Treatment options	Describe available treatments, including medication, surgery, vagus nerve stimulation (VNS) and dietary control of seizures
	Explain the importance of adherence to administration protocols and monitoring for treatment side effects
First aid management of seizures and calling 999	Demonstrate safe first aid management of seizures Explain when and how to escalate to emergency services and provide appropriate handover information
Status epilepticus (SE)	Understand the definition of SE (see Glossary) and its implications
	Recognise early warning signs of prolonged seizures and the need for timely intervention
Care planning and recording mechanisms	Recognise the role of care planning in safe practice
	Understand how to follow and update individualised emergency care plans
Risk assessment and safety	Identify key risks and propose ways to reduce them
	Apply risk assessment principles to everyday care situations to maintain safety and dignity
Sudden unexpected death in epilepsy (SUDEP)	Understand the significance of SUDEP (see Glossary) and associated risk factors Recognise the importance of communicating SUDEP information sensitively and appropriately to families and carers
Communication and dignity	Demonstrate how to maintain privacy, respect and reassurance during and after seizures
Accountability and documentation	Record seizure events and medication administration in line with organisational policy and legal frameworks
Collaboration	Identify when to seek advice from epilepsy specialists, prescribers or emergency services
Reflection and CPD	Reflect on personal learning needs and identify areas for further development
Recap and call to action – finish training on a positive note	Conclude training by reinforcing key learning points and celebrating achievements. Encourage learners to reflect on the knowledge and confidence they have gained, recognise the positive impact of their role in supporting people with epilepsy and commit to maintaining safe, person-centred practice

Buccal midazolam module (core module)

Table 3 sets out all the essential components of buccal midazolam training.

Table 3: Essential components of buccal midazolam training

Core content	Learner outcomes
What is midazolam?	Understand what midazolam is, including its pharmacological class and its status as a Schedule 3 controlled drug under the Misuse of Drugs Regulations 2001 (see Glossary)
	Explain its role as an emergency seizure medication for prolonged or cluster seizures

Core content	Learner outcomes
Indications and dosing	Identify appropriate indications for buccal (oromucosal) midazolam use as specified in individual emergency care plans
	Understand appropriate dosing by age, weight and preparation type, and know that doses must always be prescribed individually
	Recognise the different commercial preparations and concentrations
Benefits of buccal administration	Describe why buccal midazolam is preferred over rectal alternatives in most community settings (effectiveness, patient dignity, safety)
Preparation and administration technique	Demonstrate the correct steps for safe administration, including patient positioning, dose delivery and infection-prevention measures
	Maintain patient privacy and dignity throughout the procedure
	Recognise potential practical challenges (e.g. excessive salivation, resistance, single-side administration) and know appropriate responses
	Participate in a supervised practical demonstration using training equipment or simulation devices
Adverse effects and complications	Identify and respond appropriately to possible adverse effects, including respiratory depression, oversedation and allergic reaction as listed in individual medication leaflets
	Recognise when and how to escalate for medical assistance
'What if' scenarios	Explore common administration problems, such as medication dribbling out, partial dosing, vomiting or ineffective seizure control.
	Explore common side effects, such as nausea, drowsiness and confusion, as listed in individual medication leaflets
	Know what immediate steps to take and how to document and report these incidents
Care plans and communication (see Appendix VII)	Understand how to interpret and follow individual emergency care plans
	Recognise what to do if the plan appears inconsistent with seizure presentation
	Communicate clearly with emergency services and healthcare professionals, giving accurate information about timing, dose and response
Storage, security and disposal	Explain safe storage requirements and stock-control procedures under controlled-drug regulations
	Describe appropriate disposal and documentation processes, including action in the event of loss or discrepancy
Duty of care, accountability and delegation	Understand personal and organisational accountability in the administration of controlled drugs
	Recognise safeguarding implications and how to report concerns
	Identify when tasks may or may not be delegated and the boundaries of carer responsibility
Occupational safety: Control of Substances Hazardous to Health Regulations (HM Government, 2002) and use of personal protective equipment	Demonstrate knowledge of safe handling and personal protective equipment (PPE) requirements to minimise exposure risk
	Recognise and mitigate any environmental or Control of Substances Hazardous to Health (COSHH)-related hazards associated with medication handling

Core content	Learner outcomes
Recording and evaluation	Accurately document administration, outcomes and any adverse events in line with policy
	Contribute to evaluation of effectiveness and feed back to clinical leads or epilepsy services
Reflective practice and learning	Participate in reflective discussion of scenarios and case studies
	Identify areas for further personal learning or CPD to maintain competence

Optional modules

Optional content may be included, depending on the intended learners and their roles and the setting, such as:

- psychological and psychiatric comorbidities; psychosocial issues
- nasal administration of midazolam
- epilepsy in education/paediatrics; behavioural aspects
- carer risk – lack of robust training can result in physical injury, psychological distress and legal liability for the carer
- interactive case discussions
- sources of support and information, and
- administration of rectal diazepam (see specialist modules).

Optional additions for advanced level

Optional content added at advanced level may cover:

- understanding legal responsibilities under the Misuse of Drugs Regulations 2001
- applying clinical reasoning to complex scenarios (e.g. repeated doses, interactions with concurrent medications), and
- facilitating peer review and a reflective debrief following simulated administration.

Specialist modules

When considering the use of rectal preparations, it is essential to explicitly address the safeguarding implications, including the potential for misuse or sexual abuse. Any decision to proceed must be justified with clear, evidence-based reasoning and fully documented. The following principles must be applied:

1. Clear justification for why a non-rectal preparation is not in the person's best interests
2. Transparent explanation of risks and benefits to all stakeholders
3. Ensuring informed choice, or proceeding via a best-interests decision
4. Built-in regular review

Rectal diazepam (emergency use in community settings)

Rectal diazepam is a long-established emergency therapy for acute repetitive or prolonged seizures and is often prescribed in community care plans for eligible individuals. Clinical trials (e.g. Dreifuss et al., 1998) have shown significant reduction in seizure recurrence versus placebo when used by trained carers.

The absorption of rectal diazepam is known to be variable in adult patients, which can affect timing and effectiveness (Milligan et al., 1982). Administration may also be delayed by practical issues such as patient clothing, positioning and privacy, especially in older children or adults, and also by the nature of the ongoing seizures. One study noted that older children and adults may refuse rectal administration because of social or dignity concerns (Ivaturi et al., 2013). Surveys of carers suggest that their confidence and comfort levels in administering rectal diazepam vary markedly (Rossi et al., 1989).

Diazepam use must always be accompanied by an individualised emergency care plan, rigorous training, governance and clear escalation pathways to emergency care. Full procedural guidance is provided in Appendix V.

Rectal paraldehyde (specialist, exceptional use)

Rectal paraldehyde is recognised within these guidelines as a specialist and exceptional-use medication, reflecting its continued but limited administration in certain paediatric and adult settings. Its inclusion is intended to ensure that trainers and commissioners understand its governance requirements and associated risks. It is not recommended as a first-line community emergency seizure medication, and its use should only occur under the direction of a prescriber, within an individualised care plan and by staff who have received specialist training.

Evidence supporting rectal paraldehyde in community settings remains limited. A single prospective audit (Rowland et al., 2009) demonstrated seizure termination in approximately 60% of prolonged tonic–clonic seizures, with no major adverse events. However, there are no recent randomised controlled trials, and the current NICE guideline NG217 (NICE, 2022) continues to recommend buccal midazolam or rectal diazepam as the preferred emergency seizure medication options.

Where paraldehyde remains prescribed, training and administration should adhere to the governance framework and procedural steps outlined in Appendix III. Its use is subject to additional safety and practical considerations, including awareness of:

- the limited evidence base and absence of robust contemporary trials
- the potential for respiratory depression, particularly if it is given after benzodiazepines
- paraldehyde's flammable and corrosive properties, requiring COSHH and fire-risk assessment
- its chemical incompatibility with plastics, necessitating immediate administration after drawing up
- the risk of local irritation and skin soreness at the administration site, and
- practical challenges related to patient dignity and positioning and manual handling in care settings.

In view of these limitations, rectal paraldehyde should be regarded as a 'legacy' or exceptional-use intervention, retained only when clinically justified and where comprehensive oversight, documentation and staff competency can be assured.

Further details on dosing, preparation, PPE use and safe handling are provided in Appendix VI.

Other bespoke modules may be developed where clinically required.

10. Competency and learning outcomes

- Each section of the course must include defined learner outcomes.
- Care providers should use the ESNA carer competency checklist (see Section 14 and Appendix IV) to assess knowledge and skills, and support safe delegation, accountability and regulatory compliance.

Rationale
A modular format supports adult learning principles and trainer flexibility. The inclusion of SUDEP and risk assessment as mandatory components reflects their critical relevance to clinical safety and national training standards (Mayer, 2020).

11. Assessment

Assessment of learning

The Care Quality Commission requires care providers to ensure staff are suitably qualified, competent, skilled and experienced to meet the needs of service users and comply with fundamental care standards under the Health and Care Act (Regulated Activities) Regulations 2014 (HM Government, 2014).

There are recognised difficulties associated with assessing the knowledge and skills of learners undertaking buccal midazolam training. Ongoing assessment – through questioning or written assessments – during training is essential to ensure safety and carers' understanding.

Learners' knowledge and understanding should be confirmed by the trainer through a combination of:

- verbal or written questioning (pros and cons) and either:
  - practical demonstration, or
  - observation/scenario-based discussions.

Trainers may also use reflective learning activities, where appropriate.

Employers and providers are encouraged to use the ESNA carer competency checklist (see Section 14 and Appendix IV) as a standard reference tool to reinforce learning and embed good practice.

Rationale
Assessment ensures learning is embedded and observable, not assumed. It affirms the importance of direct skills validation while offering trainers options suited to the context. Assessing learning also supports audit, inspection and quality assurance processes.

12. Future developments

The 2026 guidelines will be reviewed in 2031 or sooner based on any major shift in evidence from professional bodies or stakeholders.

13. Train-the-trainer courses

The Review Committee has agreed that the Epilepsy Specialist Nurses Association (ESNA) should act as the professional body responsible for the development, endorsement and oversight of train-the-trainer (TTT) programmes in buccal midazolam training.

Purpose of TTT programmes

TTT courses are designed to enable suitably qualified HCPs, and in some cases experienced non-healthcare staff, to deliver high-quality buccal midazolam training within their organisations. The courses aim to:

- ensure trainers meet consistent national standards of competence and teaching ability
- provide a framework of accountability, governance and quality assurance, and
- safeguard the integrity of training provision by limiting TTT certification to ESNA-approved pathways in line with these guidelines.

Oversight by ESNA

- ESNA will act as the professional body responsible for developing the TTT curriculum, setting assessment standards and reviewing course content.
- ESNA will accredit TTT courses and trainers, ensuring alignment with these 2026 best practice guidelines.

- ESNA will maintain oversight of governance, including revalidation and quality assurance processes.

Standards for TTT trainers

- Healthcare professionals (HCPs): HCPs must meet the criteria set out in Section 7: Trainer competencies of these guidelines, including expert-level clinical knowledge and teaching qualifications (e.g. AET Level 3 or equivalent).
- Non-HCPs: They may undertake in-house TTT training only if they meet specified competency requirements, with ongoing clinical oversight and restricted scope of delivery.
- All trainers: They must undertake revalidation at least every two years and demonstrate evidence of continuing professional development (CPD).

Governance and accountability

- TTT courses must be delivered under proposed ESNA professional pathways currently being developed.
- Certificates of completion must be issued only under ESNA oversight.
- Accountability for the quality and safety of training extends to the TTT facilitator, the employing organisation and ESNA as the accrediting body.

Rationale

The Review Committee recognises that the quality and safety of buccal midazolam training depends heavily on the competence of trainers and the governance of TTT programmes. Feedback from the Delphi process highlighted concerns about inconsistent standards, variable oversight and the risk of commercial misuse.

By assigning ESNA the role of professional body for TTT development and accreditation, the programme gains:

- **national consistency** – a single set of standards across providers
- **robust governance** – revalidation, quality assurance and clear accountability, and
- **sustainability** – a recognised professional body able to maintain and update the programme as evidence and practice evolve.

This ensures that future trainers are trained, assessed and supported under one coherent framework, protecting the integrity of emergency seizure medication training across the UK.

14. Carer competency checklist

Overview

Ensuring that carers are competent to administer buccal (oromucosal) midazolam safely is a vital component of quality care and medicines governance. Completion of a competency assessment confirms that the carer not only attended training but can apply their knowledge and skills confidently in practice.

Competency review should be carried out by a trained reviewer who has had up-to-date epilepsy and emergency medication training and is authorised by their organisation or registered manager. The review process provides assurance to employers, commissioners and regulators that the individual has demonstrated understanding and skill in seizure management, emergency seizure medication use and record-keeping.

This checklist should be used:

- following a period of consolidation after completion of epilepsy and buccal midazolam training
- following an incident or observed practice concern, and

- as part of an annual appraisal or two-yearly refresher review.

It can also support organisational risk assessment, CQC inspection evidence and CPD/revalidation documentation.

Key principles

Competence requires both knowledge and practical skill. Successful completion of training does not automatically confer competence; it must be demonstrated through observation and discussion.

Assessment should be person-centred. The reviewer must confirm that the carer understands and follows each individual's emergency care plan accurately.

Feedback and reflection are integral. The checklist should include constructive feedback, identification of any gaps and actions for further learning.

Accountability must be clear. Care providers and registered managers retain responsibility for ensuring that only competent carers administer controlled drugs.

Regular review

Competence should be reassessed at least every two years or sooner if practice, medication formulation or the individual's emergency care plan change.

Documentation and sign-off

Completed checklists should be dated, signed by both reviewer and reviewee, and stored in personnel or training records for audit purposes.

Key areas of assessment

- **Knowledge of seizures and first aid:** This includes recognition of seizure types, safe management and maintaining patient dignity.
- **Understanding of the midazolam protocol:** This means knowing where to locate midazolam, when to administer it and when to escalate care, and recognising adverse effects.
- **Accurate timing of seizures:** This requires an understanding of the importance of timing to guide safe intervention.
- **Practical administration skills:** These include correct technique, PPE use, infection control and monitoring.
- **Storage, recording and disposal:** This involves compliance with organisational medicines policies and controlled-drug requirements.
- **Communication and documentation:** This covers accurate reporting, effective handover and incident escalation.
- **Reflection and professional behaviour:** This means acknowledging limitations, seeking help appropriately and maintaining competence through CPD.

Further information

For details of the national competence assessment tool and guidance on its use, see Appendix IV, which links to the current version of the ESNA Competency checklist for the administration of buccal (oromucosal) midazolam (for carers).

Rationale
Competency assessment ensures carers can apply learning in real-world scenarios, reducing medication errors and safeguarding patients during seizures. It supports consistent standards across services, aligns with national regulatory expectations and promotes a culture of safety, accountability and continuing professional development.

15. Plans for audit and review

These guidelines will be reviewed by ESNA every three years as part of ongoing best practice for the safe management and delivery of emergency seizure medication within the community.

During this review, ESNA will collate and analyse feedback and documented deviations from standards submitted by training providers, commissioners and epilepsy practitioners to identify themes, lessons learned and opportunities to strengthen guidance and promote resilience across services.

16. Conclusion

This is a revised and edited document expanding on the 2023 guidelines (ESNA, 2023a). It provides improved best practice guidance that should form the core of any epilepsy training course, including TTT programmes, and sets out standards to ensure the safe administration of emergency seizure medication in the community.

The guidelines also encourage a culture of reflective learning and open feedback, recognising that sharing justified deviations and innovations strengthens collective safety and supports the evolution of best practice. In addition, they provide guidance for commissioners to ensure the best possible standards of epilepsy and emergency seizure medication training.

17. Glossary

Accountability

Clear assignment of responsibility for ensuring that training and care practices meet agreed standards, extending to trainers, training providers, commissioners and prescribers.

Assessment

Process of evaluating whether a learner has the required knowledge, skills and confidence to safely administer buccal midazolam and provide seizure care. Methods include questioning, observation and practical demonstration.

Blended learning

An educational approach that combines traditional face-to-face instruction with online or digital learning methods to create a more flexible, interactive and effective learning experience.

Buccal (oromucosal) midazolam

An emergency seizure medication used to stop prolonged or cluster epileptic seizures. It is administered into the buccal cavity (between the gum and cheek). Recognised as the first-line treatment in community settings (NICE, 2022).

Care competency checklist

A structured tool developed by ESNA to support employers and providers in assessing, recording and maintaining staff competence in epilepsy and emergency seizure medication care.

Carer (professional carer)

A paid worker providing care and support for people with epilepsy in community, residential or educational settings. Distinct from family or informal carers.

Clinical oversight

The responsibility of a suitably qualified healthcare professional to review, supervise and assure the quality and safety of training or care delivery.

Commissioner

An individual or organisation that purchases or contracts services (e.g. training, health or social care) on behalf of a population or group.

Competence

Competence in epilepsy training refers to a learner's ability to consistently apply the knowledge, skills, behaviours and professional judgement required to perform clinical tasks safely and effectively in real-world practice. It means the learner can carry out a task reliably, independently and to an agreed professional standard, while recognising their limits and seeking help appropriately.

Competency framework (ESNA)

A structured framework developed by ESNA that defines levels of clinical and teaching competence (novice, competent, expert) for epilepsy specialist nurses and trainers, and is used to benchmark training roles.

Controlled drug

A medication subject to legal controls under the Misuse of Drugs Act 1971 and associated regulations, due to the potential for misuse. Buccal midazolam is a Schedule 3 controlled drug in the UK under the Misuse of Drugs Regulations 2001.

Cluster seizures

There is no single universal definition for this term. Cluster seizures (also called seizure clusters or acute repetitive seizures) are multiple seizures occurring within a specified period of time, with the person returning to baseline between episodes.

Delphi process

A structured method for achieving consensus among experts and stakeholders. When revising these guidelines, the process included surveys, questionnaires and iterative discussions to refine recommendations.

Emergency care plan (care plan)

An individualised written plan developed by clinicians, people with epilepsy, their families and carers. It outlines when and how emergency medication should be administered, what dosage is recommended and when to seek further medical help.

Epilepsy Specialist Nurses Association (ESNA)

The professional body representing epilepsy specialist nurses in the UK. ESNA is responsible for producing these guidelines and accrediting train-the-trainer courses. An Epilepsy specialist nurse (ESN) is a registered nurse with advanced expertise in epilepsy care, responsible for clinical management, education and training.

Healthcare professional (HCP)

An individual who is qualified, registered or licensed to provide health-related care, treatment, advice or services to patients or the public, in line with national or professional regulations.

Optional modules

Training content that can be included in addition to the mandatory core modules, tailored to learner role, service setting or specific needs (e.g. psychosocial issues, epilepsy in education).

Prolonged seizure

There is no single universal definition for this term. A prolonged seizure is a continuous clinical seizure lasting two to three minutes longer than the individual's usual seizure presentation or two or more repeated seizures without recovery of consciousness between them.

Rectal diazepam

An alternative emergency seizure medication for epilepsy, used especially in paediatrics and certain care settings. Recognised by NICE guidance.

Rectal paraldehyde

An older type of emergency seizure medication, now used rarely in specialist paediatric and adult settings. Included only as a specialist module (see Appendix VI) due to risks in administration.

Refresher training

Update training, normally completed every two years, to maintain competence and incorporate new evidence, clinical standards and practice developments.

Rescue medication (emergency seizure medication)

Medication given to terminate a seizure or cluster of seizures outside of hospital, typically buccal midazolam or rectal diazepam.

Status epilepticus (SE)

Status epilepticus (SE) is a medical emergency defined as a seizure lasting longer than five minutes, or multiple seizures occurring close together without the person regaining consciousness in between. It indicates a failure of seizure-termination mechanisms, requiring immediate intervention to prevent neuronal damage, which can begin after five minutes (BNF, undated).

Sudden unexpected death in epilepsy (SUDEP)

The sudden and unexpected death of a person with epilepsy, where no other cause of death is found. SUDEP awareness and risk-reduction strategies are part of mandatory training.

Total learning hours (TLHs)

As defined by the Office of Qualifications and Examinations Regulation (Ofqual), TLHs represent the notional number of hours that an average learner is expected to take to complete a qualification or training course. This includes both guided learning hours (direct teaching or supervision) and independent study time, in line with the Regulated Qualifications Framework (RQF).

Train-the-trainer (TTT) courses

Accredited programmes that prepare HCPs (and in some cases experienced non-HCPs) to deliver buccal midazolam training. Developed, endorsed and overseen by ESNA.

Trainer

An individual responsible for delivering epilepsy and emergency seizure medication training, who must meet defined competencies and revalidation requirements as set out in these guidelines.

18. Sources of further information

Note: The organisations below are included to signpost readers to wider sources of information, advice and support relating to epilepsy. Inclusion in this list does not constitute formal endorsement by ESNA. Readers are encouraged to verify that any external training or materials align with ESNA best practice standards and relevant national guidelines.

Epilepsy Action
New Anstey House
Gate Way Drive
Yeadon
Leeds LS19 7XY
Helpline: 0808 800 5050
Website: www.epilepsyaction.org.uk
Email: epilepsy@epilepsyaction.org.uk

Epilepsy Action Cymru
Website: www.epilepsy.org.uk/support-for-you/epilepsy-action-cymru-wales

Epilepsy Specialist Nurses Association (ESNA)
Website: www.esna-online.org.uk
Email: esnaepilepsynursesassociation@outlook.com

Epilepsy Society
Chesham Lane
Chalfont St Peter SL9 0RJ
Helpline: 0300 102 0024
Website: www.epilepsysociety.org.uk
Email: helpline@epilepsysociety.org.uk

Epilepsy Scotland
48 Govan Road
Glasgow G51 1JL
Helpline: 0808 800 2200
Website: www.epilepsyscotland.org.uk
Email: enquiries@epilepsyscotland.org.uk
Enquiries: 0141 427 4911

International League Against Epilepsy (ILAE) British Branch
6 Inverforth House
North End Way
London NW3 7EU
Website: http://ilaebritish.org.uk
Email: members@ilaebritish.org.uk

International League Against Epilepsy (ILAE) Nursing Section
Website: www.ilae.org/nursing-section
Email: ilaenurses@gmail.com

Young Epilepsy
St Piers Lane
Lingfield
Surrey RH7 6PW
Helpline: 01342 831342
Website: www.youngepilepsy.org.uk
Email: info@youngepilepsy.org.uk

Quarriers
The William Quarrier Scottish Epilepsy Centre
20 St Kenneth Drive
Glasgow G51 4QD
Tel: 0141 445 7750
Website: www.quarriers.org.uk/blog/service/epilepsy-and-neurology
Email: scottishepilepsycentre@quarriers.org.uk

Neuraxpharm (Buccolam®)
Website: www.neuraxpharm.com/uk/portfolio

SERB Pharmaceuticals (Epistatus®)
Tel: 01932 690325
Website: https://epistatus.co.uk/healthcare-professional
Email: epistatus@serb.com

Royal College of Psychiatrists (RCPsych)
Tel: 0208 618 4000
Website: www.rcpsych.ac.uk

Royal College of General Practitioners
Tel: 020 3188 7400
Website www.rcgp.org.uk

SUDEP Action
12A Mill Street
Wantage OX12 9AQ
Tel: 01235 772850
Website: https://sudep.org
Email: info@sudep.org

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This document has been developed in accordance with:

- the Nursing and Midwifery Council (NMC) code of professional standards (NMC, 2018), and
- National Institute for Clinical Excellence (NICE) guideline NG217 (NICE, 2022).

Appendix I: Major changes since last publication

ESNA midazolam training guidelines: Executive summary

1. Scope and structure

The 2026 version is presented as the third edition, consolidating and replacing the 2019 and 2023 editions.

- Broader in scope: This version is now titled Best practice guidelines for professional carers in emergency seizure medication, reflecting the inclusion of rectal diazepam and reference to paraldehyde alongside buccal midazolam.
- Expanded and restructured contents: New sections have been added on guiding principles, methodology, competence and learning outcomes, future developments and train-the-trainer courses, plus a glossary.
- Appendices: These have been reorganised and expanded to include materials for commissioners, employers and providers, such as the ESNA carer competency checklist.

2. Introduction and context

The introduction has been substantially rewritten to emphasise the clinical importance, national variation and regulatory implications of emergency seizure medication training.

This edition integrates findings from the 2025 Rescue Epilepsy Medication and Training (REMIT) study and references Learning from Lives and Deaths (LeDeR) reports and Care Quality Commission (CQC) expectations, situating training within broader patient safety and equality frameworks.

The tone and focus have shifted from procedural guidance to a strategic, evidence-based standard for national consistency.

3. Guideline principles and methodology (new sections)

The new guideline principles section (Section 4) articulates national aims, inclusivity, accountability and safety standards.

The new methodology section (Section 5) outlines how a Delphi consensus process, stakeholder engagement and an AI-assisted evidence review were used in developing the latest guidelines, enhancing transparency.

4. Standards for commissioning or delivering training

The guidelines have been rewritten for clarity and to support accountability. They set out standards that:

- emphasise the responsibility shared between commissioners, trainers and providers
- require any deviation from standards to be documented and justified
- include explicit expectations for prescribers and commissioners regarding training oversight, and
- incorporate a ‘responsibilities at a glance’ summary table for quick reference.

5. Trainer competencies

These have been fully revised and aligned with the ESNA nurse competency framework levels (novice–competent–expert). The guidelines now:

- introduce a tiered model (Groups 1–4b) defining minimum experience, teaching qualifications and governance for each trainer level
- replace line manager sign-off with peer clinician endorsement
- include a two-year revalidation cycle across all trainer levels
- clarify inclusion criteria and restrictions for non-HCP trainers (Groups 4a and 4b)

- specify AET Level 3 (or equivalent) as the minimum qualification for train-the-trainer facilitators, and
- embed governance expectations in the main guidance.

6. Delivery of training

The latest guidelines reaffirm face-to-face delivery as the gold standard, while explicitly permitting blended or live virtual models under defined conditions.

Online-only, pre-recorded courses remain an unacceptable form of training for those administering emergency seizure medication.

There is a new differentiation between high-risk (direct medication administration) and low-risk (general awareness only) settings, and guidance has been added on tailored delivery models for awareness-level staff.

7. Duration and structure

The guidelines:

- confirm requirements for a minimum of six hours of initial training and at least three hours of refresher training every two years
- add the flexibility to tailor refresher content to a learner's role, competence and setting, and
- introduce the optional use of pre-course materials (e.g. short case studies or videos).

8. Course components

Training has been reorganised into a modular format.

- Core modules (mandatory): These cover epilepsy awareness, seizure management, SUDEP, risk assessment, care planning and buccal midazolam administration.
- Optional modules: These may include psychosocial issues, psychiatric comorbidities and paediatric/educational aspects.
- Specialist modules: These cover rectal paraldehyde and other emergency seizure medications. Specific guidance is given in Appendix V (rectal diazepam) and Appendix VI (paraldehyde).

The buccal midazolam module has been expanded to include:

- the step-by-step administration process
- governance and controlled-drug requirements
- personal protective equipment (PPE) and occupational safety considerations, and
- 'what if' scenarios for incomplete or ineffective doses.

9. Assessment

This latest version removes references to the discontinued online ESNA test. This test was withdrawn due to low user numbers and lack of funding.

It establishes a multi-method approach (verbal/written questions, observation) and embeds use of the ESNA carer competency checklist (see Appendix IV) as the national assessment reference tool.

10. Train-the-trainer (TTT) courses

The TTT section of the guidelines (Section 13) has been significantly expanded and updated. It now:

- formally designates ESNA as the professional body for the development, accreditation and oversight of all TTT programmes
- defines standards for HCP and non-HCP TTT participants, revalidation every two years and ESNA approval of certificates

- is reinforced by a separate appendix (Appendix III) for commissioners, summarising TTT governance for use in tenders or service specifications, and
- replaces detailed operational tables from the 2023 edition with a concise, standardised governance model.

11. Future developments

The latest guidelines include new placeholder content acknowledging anticipated NICE updates on nasal and intramuscular midazolam, signalling future guideline integration.

12. Appendices and supporting tools

Appendix I: Major changes since last publication

Appendix II: Methodology and Delphi consensus findings

Appendix III: Train-the-trainer summary for commissioners

Appendix IV: Using the carer competency checklist

Appendix V: Administration of rectal diazepam

Appendix VI: Administration of rectal paraldehyde 50:50 mix with olive oil enema or rectal solution

Appendix VII: Example buccal midazolam emergency care plan

Appendix VIII: Example training evaluation feedback form

Appendix IX: Contributors and acknowledgements

This latest edition of the guidelines does not include survey results and detailed TTT course design tables, which appeared as appendices in the 2023 version.

13. Glossary

A comprehensive glossary defining key terms (e.g. competence, accountability, controlled drugs, SUDEP) has been added to the guidelines (Section 17), enhancing accessibility and regulatory alignment.

14. References and sources

The references and sources used in this edition have been updated to include the Rescue Epilepsy Medication and Training (REMIT) study (McBride et al., 2025) and to remove superseded references from the Covid-19 pandemic period.

This latest version retains core National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN) and Nursing and Midwifery Council (NMC) references and maintains alignment with NICE guideline NG217 (NICE, 2022).

15. Overall presentation and emphasis

The 2026 guidelines are more structured, evidence-driven and governance-oriented, with emphasis on:

- national consistency, regulatory accountability and quality assurance, and
- ESNA as the recognised professional body.

Appendix II: Methodology and Delphi consensus findings

Guideline development process

Revision of the Epilepsy Specialist Nurses Association (ESNA) Best practice guidelines for professional carers in emergency seizure medication: Training standards for the safe administration of buccal (oromucosal) midazolam in the community was undertaken using a structured guideline development process incorporating stakeholder engagement, evidence review and a modified Delphi consensus methodology. This approach was selected to ensure transparency, methodological rigour and broad professional input, while enabling structured consensus development in areas where practice variation exists.

The review aimed to strengthen clinical governance, standardise training expectations and enhance clarity regarding competency assessment and service delivery standards.

Stakeholder engagement and expert panel

ESNA invited expressions of interest to participate in the guideline review through its weekly member newsletter, epilepsy charities, condition-specific organisations and education and training providers known to the association. All individuals and organisations expressing an interest were invited to join the review process.

A Core Best Practice Revision Group of 14 members was subsequently established to act as an expert panel. The group was structured to ensure representation across relevant stakeholder groups and equal representation from adult and paediatric epilepsy specialist nurses (ESNs).

This expert panel included:

- ESNs (adult and paediatric services)
- clinicians with prescribing and governance responsibilities related to rescue medication
- education and training leads responsible for delivery of midazolam training programmes, and
- contributors with experience in competency assessment, regulatory compliance and service governance.

Members represented a range of service contexts, including acute hospital services, community epilepsy teams, specialist tertiary services and independent training providers.

Review process

The Core Best Practice Revision Group met monthly through virtual meetings, each lasting about an hour, over a six-month period. During these meetings, participants reviewed existing guideline sections, discussed proposed revisions and provided structured feedback on draft material.

Members unable to attend meetings could contribute via written feedback submitted electronically. Meeting transcripts, written comments, peer-reviewed literature, email correspondence and survey responses were collated to inform the review process.

Development of Delphi statements

The existing midazolam best practice guidelines (from 2019 and 2023) were systematically reviewed to identify areas requiring clarification, updating or consensus. Particular focus was given to:

- areas where variation in national practice existed;
- governance-related wording requiring strengthening;
- sections relating to training delivery and competency assessment; and
- operational aspects of rescue medication administration in community settings.

Proposed amendments were drafted as discrete statements suitable for Delphi evaluation. Supporting rationale was provided where necessary to contextualise proposed changes.

Delphi consensus procedure

A modified Delphi approach was used to obtain structured expert consensus.

- **Round 1**

  Delphi questionnaires were circulated electronically using structured documents and online survey tools. Participants were asked to indicate their level of agreement with each statement (agree/agree with modification/disagree) and to provide qualitative comments or suggested wording amendments where appropriate.

  Responses were anonymised prior to analysis to minimise dominance bias and encourage independent expert input.

- **Data analysis and iterative review**

  Quantitative agreement levels were reviewed descriptively. Agreement percentages were interpreted alongside qualitative feedback, particularly where patient safety, governance or regulatory considerations were raised.

  Free-text responses were analysed thematically to identify recurring concerns, areas of ambiguity and suggested refinements. Revised wording was drafted and circulated to the revision group for further consideration.

  Draft summaries and suggested rewording were then distributed to the group prior to subsequent meetings to support structured discussion.

- **Round 2**

  Statements not achieving clear consensus or requiring substantial modification following Round 1 were redistributed for further review. Summary anonymised feedback from the first round accompanied each revised statement to facilitate informed reconsideration.

  Where significant disparities of opinion emerged, additional focused discussions were undertaken and, where necessary, additional core revision group meetings were convened to clarify issues and review available evidence.

Definition of consensus

Consensus was defined pragmatically as:

- clear majority agreement among respondents
- absence of unresolved patient safety concerns; and
- no substantive objections that could not be addressed through wording refinement.

Where appropriate, statements were modified to reflect professional discretion while preserving minimum safety standards.

Use of artificial intelligence (AI)

Artificial intelligence (AI) tools (ChatGPT Pro) were used to support the organisational and editorial aspects of the review process. AI assistance contributed to:

- collation and structuring of expert panel responses
- synthesis of qualitative feedback
- drafting of summary documents and proposed wording revisions; and
- identification of areas of agreement or disagreement to inform further Delphi questioning.

AI tools did not independently generate clinical recommendations or determine consensus outcomes. All decisions regarding the content and wording of the guidelines were made by the expert panel.

Governance and oversight

Governance of the guideline development process was maintained by the ESNA Executive. Regular updates were provided to the Executive throughout the review to ensure transparency and alignment with organisational standards.

A structured audit trail documenting the evolution of guideline statements across Delphi rounds was maintained to support methodological transparency.

Ethical considerations

The guideline revision involved professional consensus development and did not involve patient-level data collection. Formal research ethics approval was therefore not required. Participation by panel members was voluntary.

Delphi consensus findings

- **Overview**

  The Delphi process generated both quantitative and qualitative data across multiple rounds of consultation. Response numbers varied by topic, reflecting phased and targeted consultation (n=15, n=25, n=9 and n=3 across different rounds).

- **Course content**

  There was strong consensus that the existing course content provides an appropriate foundation for epilepsy training. A clear majority of respondents (93.3%) agreed that current content meets the needs of people with epilepsy, their carers and families.

  Qualitative feedback identified areas for enhancement rather than replacement. Recurring themes included the inclusion of psychological and psychiatric comorbidities, paediatric and educational considerations, carer-related risks and increased use of visual and practical teaching methods.

  There was also strong support for strengthening educational structure, including the addition of defined learner outcomes (80%) and the incorporation of a formal competency framework (73.3%).

- **Training delivery**

  Consensus supported face-to-face training as the preferred modality. The majority of respondents (52%) favoured face-to-face delivery with virtual options permitted only under exceptional circumstances, while 20% supported a blended model.

  Strong agreement was observed regarding the conditions required for any non-face-to-face delivery, including real-time interactivity (88%), access to demonstration materials (92%) and validation of practical skills.

  There was no clear consensus regarding online-only training; however, responses favoured restricting its use or requiring in-person follow-up, reinforcing the importance of practical competence.

- **Training duration and adaptation**

  Views on training duration were mixed. While 48% supported the current six-hour recommendation for initial training, others supported modular or flexible approaches depending on learner experience.

  Refresher training was broadly supported in its current format (52%), though many respondents indicated a need for greater flexibility and adaptation to reflect increasing complexity of care.

  A majority supported allowing trainers discretion to tailor refresher training based on learner experience.

- **Assessment and competency validation**

  There was strong agreement on the importance of practical assessment. Practical demonstration was supported by 80% of respondents, alongside verbal questioning, written assessment and other multimodal approaches.

  These findings support a blended assessment model with emphasis on observed competence.

- **Trainer competency and governance**

  Responses relating to trainer eligibility demonstrated variation. While a majority supported restricting training delivery to healthcare professionals (66.7%), there was no clear consensus on excluding non-healthcare professionals entirely.

  There was moderate to strong support for:

  - a national train-the-trainer programme (66.7%), and
  - governance and accreditation mechanisms (66.7%).

  These findings informed a balanced approach incorporating flexibility alongside strengthened governance safeguards.

- Focused subgroup analysis

  A smaller, targeted subgroup explored complex governance issues. All participants prioritised clinical safety and accuracy. Conditional support was expressed for non-healthcare trainers operating within structured governance frameworks, though no consensus was reached on tiered competency models.

Areas of consensus and divergence

Strong consensus was observed in relation to the:

- validity of existing course content
- importance of face-to-face and practical training
- need for competency-based assessment, and
- inclusion of structured learner outcomes.

Areas of divergence included:

- trainer eligibility
- degree of prescriptive guidance
- training duration and format, and
- role of virtual and online learning.

Where divergence occurred, iterative discussion enabled development of pragmatic and defensible recommendations.

Strengths and limitations

The Delphi approach enabled geographically dispersed expert input while reducing the influence of hierarchical dynamics. The iterative structure allowed refinement of complex governance and training issues and strengthened the defensibility of final recommendations.

Limitations included reliance on expert opinion and variability in response numbers across consultation rounds. However, the use of mixed quantitative and qualitative data, anonymised feedback and iterative consensus processes mitigated these limitations.

Appendix III: Train-the-trainer (TTT) summary for commissioners

This appendix is written in a way that enables commissioners to lift the content directly into tender documents, service specifications or audits.

Purpose of TTT courses

Train-the-trainer (TTT) programmes equip healthcare professionals (HCPs) – and in some cases experienced non-HCPs under defined conditions – to deliver buccal midazolam training safely and effectively within their organisations.

ESNA's role

- ESNA is the professional body responsible for developing, accrediting and overseeing all TTT programmes.
- ESNA sets the curriculum, assessment standards and governance requirements.
- ESNA provides revalidation and quality assurance to ensure nationwide consistency.
- Standards for TTT trainers
- HCPs: Must meet expert-level clinical standards (as specified by ESNA competency frameworks) and hold a recognised teaching qualification e.g. Award in Education and Teaching (AET) Level 3.
- Non-HCPs: May only deliver in-house training after completing an ESNA-approved TTT course, with clinical oversight and restricted scope.
- All trainers: Must revalidate every two years and evidence their continuing professional development (CPD).

Accountability

- TTT programmes must be ESNA-approved and delivered under a regulated framework.
- Responsibility for training quality and safety lies with:
    - the TTT facilitator/trainer
    - the employer organisation, and
    - ESNA as the accrediting body.
- Certificates of completion are issued only under ESNA oversight.

Key benefits for commissioners

- Assurance that training provision is aligned to national best practice.
- Confidence in trainer competence and governance.
- Reduced variation and risk across providers.
- A sustainable, evidence-based framework with oversight from the recognised professional body.

Appendix IV: Using the carer competency checklist

Overview

Ensuring that carers are competent to administer buccal (oromucosal) midazolam safely and effectively is a critical component of epilepsy care and medicines governance. Competency assessment verifies that the carer can apply the knowledge and practical skills gained in training within real-world settings, maintaining safety, patient dignity and adherence to prescribed protocols.

ESNA's Competency checklist for the administration of buccal (oromucosal) midazolam (for carers) provides a structured tool to support observation, discussion and review of practice.

It should be used:

- following completion of initial or refresher training
- when a carer's competence requires confirmation after an incident or a change in medication/ protocol, and
- as part of an annual supervision or appraisal process.

Competency assessment must be undertaken by a reviewer who is trained and authorised by their organisation and who has had up-to-date epilepsy and emergency medication training.

What the ESNA carer competency checklist covers

The ESNA checklist provides the national standard framework for assessing competency.

It reviews a carer's:

- knowledge of seizures and first aid
- understanding of individual emergency protocols
- practical administration techniques and timing
- recognition of adverse effects and the need for escalation
- recording, storage and disposal of medication, and
- accountability, communication and reflective practice.

The checklist also includes model questions, reviewer guidance and optional case studies to support learning and assessment.

Accessing the checklist

The current version of the checklist (ESNA, 2022) can be downloaded directly from the ESNA website. The document is version-controlled, dated and reviewed at least every two years.

Organisations may adapt the ESNA template with their logo or additional governance details for local use, provided that the content remains consistent with ESNA best practice standards.

Rationale
Embedding a structured competency assessment within training and supervision promotes safety, accountability and consistent standards across services. It ensures that carers not only attend training but can demonstrate safe, person-centred practice, aligning with NICE's NG217 guideline and CQC (2023) and ESNA recommendations for medication administration in epilepsy care.

Appendix V: Administration of rectal diazepam (specialist, exceptional use)

Scope and status

Rectal diazepam is a long-established, licensed medication used for acute repetitive or prolonged seizures, particularly in community or home settings. It remains an accepted option in national guidance (NICE, 2022) for individuals where buccal or intranasal midazolam is unsuitable, unavailable or ineffective.

Administration must follow an emergency seizure medication administration care plan, with clear parameters for timing, dosage and escalation. Trained carers and healthcare staff must complete specialist training before administration.

Indications (specialist/emergency use)

Rectal diazepam is indicated for use:

- for individuals with known prolonged or cluster seizures at risk of recurrence
- as part of a documented emergency care plan specifying the timing and dosage
- when buccal midazolam cannot be used, and
- by trained carers or healthcare staff in community or educational settings.

Contraindications/caution

Rectal diazepam is contraindicated in cases of:

- hypersensitivity to diazepam or benzodiazepines
- severe respiratory or hepatic impairment, or
- concurrent use of other central nervous system (CNS) depressants – monitor closely for respiratory depression.

It should be used only via the rectal route, never intravenously.

It should be used with caution in infants or underweight patients – dose adjustment is required.

Governance and consent

- Rectal diazepam should only be administered in accordance with a prescribed and signed emergency seizure medication care plan.
- Staff must be trained to administer rectal diazepam in line with the 2026 ESNA best practice guidelines for professional carers in emergency seizure medication.
- Consent and best-interest decisions must be documented where capacity is lacking.
- Each dose given must be recorded and reported to the prescriber or service lead.
- For adults who lack capacity, because rectal administration is intrusive and engages issues of privacy, dignity and bodily integrity, the decision to include rectal diazepam within an emergency care plan should be subject to enhanced governance oversight. In addition to best-interests decision-making and multidisciplinary team (MDT) agreement, the rationale for its use should be discussed with relevant professional peers or specialist colleagues, and the organisation responsible for prescribing and authorising the care plan should ensure that an appropriate legal and policy review has been undertaken.

Evidence summary

- The Dreifuss study (Dreifuss et al., 1998) found that rectal diazepam gel significantly reduced acute repetitive seizure recurrence compared with a placebo (71% seizure-free vs. 28% placebo) in community-based trials.
- A randomised trial (Scott et al., 1999) found both rectal diazepam and buccal midazolam were effective in treating prolonged seizures in childhood and adolescence.

- Long-term real-world use demonstrates the safety and efficacy of rectal diazepam when delivered by trained carers.

Limitations

Administration of rectal diazepam may be limited by:

- manual handling considerations
- absorption variability – there may be delayed onset if large stool volume present, and
- privacy and dignity considerations.

There has been a shift to using buccal or intranasal benzodiazepines for reasons of practicality and social acceptability.

Preparation, storage and handling

- Rectal diazepam is supplied as prefilled rectal gel syringes (e.g. Diazepam RecTubes, Diastat, Stesolid).
- Do not transfer contents to another container or syringe.
- Check the label, strength and expiry date before use.
- Store at room temperature, away from heat and direct sunlight.
- Discard if the seal is broken or the gel is discoloured.

Equipment (minimum)

Equipment for administration should include:

- prefilled diazepam rectal tubes (dose per care plan)
- disposable gloves
- a towel or pad for patient privacy and dignity
- a care plan outlining time, dose and usual response, and
- the dose (following the care plan); in children this must match the individual's weight-based prescription.

Common doses

Common doses are:

- children 1–5 years: 5mg
- children 6–11 years: 10mg
- ≥ 12 years/adults: 10–20 mg.

Repeat dosing is only recommended if this is specifically authorised in the care plan (typically after 4–12 hours).

Always escalate if seizures persist beyond the prescribed time frame.

Administration

A summary for trained staff:

- Position the person safely on their left side (i.e. in the recovery position) if possible.
- Ensure the patient has enough privacy.
- Put on protective gloves.
- Remove the medication tube cap.

- Gently insert the tube into the rectum to the marked line, if there is one; this indicates the age-appropriate depth for insertion.
- Squeeze the rectal tube gently, and keep squeezing to prevent medication being withdrawn from the bowel.
- Withdraw the tube gently, then keep the patient's buttocks together for 10–30 seconds.
- Keep the patient in the recovery position, observing their breathing and seizure activity.
- Dispose of used tube safely.
- Remove and dispose of gloves and wash hands.
- Call 999 if the seizure continues or breathing is compromised.

Aftercare and monitoring

- Continue to monitor the patient until full recovery.
- Record any drowsiness, respiratory depression or adverse effects.
- Ensure supervision until the person is fully alert.
- Notify the prescriber if diazepam is ineffective or poorly tolerated.

Safety notes for trainers to emphasise

- Respect for the patient's dignity and privacy is paramount.
- There must be a manual handling risk assessment if carers are being asked to lift an individual in seizure so they can administer this medication.
- Respiratory monitoring is essential after administration.
- Effectiveness can vary depending on rectal absorption – always follow escalation protocols.
- Never share doses between patients.
- Carers must know how and when to call emergency services.

Training and competency

ESNA expects that:

- Training must be delivered only by qualified nurse trainers with experience in epilepsy care.
- Learners must demonstrate competence via simulation and assessment checklists.
- Refresher training is carried out every two years.
- There is interface with emergency services.
- The care plan must specify when to dial 999 and what information to provide.
- Ambulance staff must be informed of the time, dose and formulation given. Paramedics may continue treatment if seizures persist.

Documentation and audit

- Record dose, time, effect and any adverse reactions.
- Report all administration to the clinical lead or prescriber.
- Include administration in periodic service audits of anti-seizure medication use.

Key references

- NG217: Epilepsies in children, young people and adults (NICE, 2022)
- 'A comparison of rectal diazepam gel and placebo for acute repetitive seizures' (Dreifuss et al., 1998)

- ‘Buccal midazolam and rectal diazepam for treatment of prolonged seizures in childhood and adolescence: a randomised trial’ (Scott et al., 1999)
- Diazepam (rectal) for stopping seizures (Medicines for Children, 2015)
- ‘The community use of rescue medication for prolonged epileptic seizures in children’ (Klimach, 2009)
- Competency checklist for the administration of buccal (oromucosal) midazolam, (ESNA, 2022)

Appendix VI: Administration of rectal paraldehyde 50:50 mix with olive oil enema or rectal solution (specialist, exceptional use)

Key message

- • Rectal paraldehyde is reserved for exceptional circumstances where first-line emergency medications are contraindicated or ineffective. Its use requires specialist training, a Control of Substances Hazardous to Health (COSHH) risk assessment and an emergency seizure protocol signed by the prescriber.

1. Scope and status

Paraldehyde is a sleep-inducing hypnotic and sedative with anticonvulsant effects. It is used to treat seizures or control status epilepticus (SE) resistant to conventional treatment.

Rectal paraldehyde is only used in tightly controlled, specialist-led situations. Current evidence and national bodies do not recommend it in modern first-line or second-line seizure-management pathways. Rectal paraldehyde is not recommended in national UK guidance and is only used in specialist-led, protocol-driven circumstances for selected patients with individualised emergency protocols.

There is no licence for paraldehyde as an enema within the UK. Therefore, the preparation is classed as a 'special' or is imported by a licensed pharmaceutical company. There needs to be individual prescription preparation, including careful checking of the dose, volume and instructions.

2. Indications (specialist circumstances only)

- Standard first-line treatments (buccal midazolam/rectal diazepam) have failed or are contraindicated.
- The individual has a prescriber-approved emergency protocol specifying rectal paraldehyde.

3. Contraindications and cautions

- Use caution:
  - if the individual has known or suspected liver disease (as it may lead to decreased clearance)
  - if the individual has significant respiratory compromise (up to 30% of the drug is excreted through the lungs, which explains odour on the breath).
- Paraldehyde is contraindicated for individuals:
  - with colitis, as it may aggravate the condition (BNF for Children, undated)
  - with hypersensitivity to paraldehyde
  - also prescribed disulfiram (used in chronic alcohol disorders).

⚠ Do not use neat paraldehyde — only use the pharmacy-supplied 50:50 mixture with olive oil.

Caution: The solution must not be used if it has brown discolouration or smells of vinegar. Paraldehyde is toxic once it has broken down (e.g. past its use-by date).

4. Governance and consent

- Paraldehyde administration should only be initiated by secondary or tertiary care.
- It must only be used under a named prescriber's protocol, with an explicit clinical rationale and documented risk assessment.
- The privacy and dignity of the individual must be prioritised.
- A manual handling risk assessment must be completed for the administration of rectal paraldehyde.

For adults lacking capacity, its use must be agreed as being in their best interests, following a multidisciplinary team (MDT) discussion, and documented accordingly.

For adults who lack capacity, because rectal administration is intrusive and engages issues of privacy, dignity and bodily integrity, the decision to include rectal paraldehyde within an emergency care plan should be subject to enhanced governance oversight. In addition to best-interests decision-making and MDT agreement, the rationale for its use should be discussed with relevant professional peers or specialist colleagues, and the organisation responsible for prescribing and authorising the care plan should ensure that an appropriate legal and policy review has been undertaken.

A COSHH risk assessment must be completed to protect the administrator from potential harm. Refer to paraldehyde safety data sheet (SDS) risk information available from individual manufacturers (Sigma-Aldrich, 2026; Huddersfield Pharmacy Specials, 2016).

5. COSHH risk assessment

The assessment should include the risks and control measures outlined in Table 4.

Table 4: Hazards and actions to consider in paraldehyde risk assessment

Hazard	Precautions and actions
Flammability	Flammable liquid and vapour Keep container closed, away from heat, naked flames and sunlight
Skin irritation	Wear nitrile gloves and an apron Wash any skin contact immediately with cold running water for 15 minutes If irritation occurs, seek medical advice
Eye irritation	Wear eye goggles or face protection Rinse any eye contact with water for at least 15 minutes Remove contact lenses, if present and it is easy to do so If irritation occurs, seek medical attention immediately
Inhalation	Vapour is an irritant and potentially flammable Use in a well-ventilated area Remove the patient to fresh air and seek medical advice if necessary Apply artificial respiration if breathing stops
Decomposition	Discard if solution darkens, turns brown or smells of vinegar
Incompatibility with plastics	Only draw up immediately before use and discard if in syringe more than 10 minutes

6. Preparation, storage and handling

Paraldehyde should be supplied as a 50:50 mix with olive oil (see Figure 1). Do not use neat.

Figure 1: Example of paraldehyde and olive oil mix

- Storage
  - Store upright in the original container.
  - Store in a well-ventilated area and keep containers closed when not in use.
  - Store below 25°C.
  - Do not store in a refrigerator as paraldehyde solidifies to form a crystalline mass at 12°C and olive oil will form a precipitate.
  - Protect from light.
- Handling
  - Wear suitable protective equipment (e.g. disposable nitrile gloves and chemical-resistant safety glasses or goggles).
  - Avoid inhalation of vapour or mist.
  - Avoid contact with eyes, skin and clothing.
  - Keep away from sources of ignition – no smoking.
- Preparation
  - Confirm prescription details, including name, drug, route, expiry date and hazard warnings.
  - Ensure the seal of the bottle is intact.
  - Do not use solution if it is brown, smells of vinegar or is past its expiry date.
  - Rectal paraldehyde is a single dose only. A new bottle will be required for each dose. Discard partly used bottles for later disposal.
- Disposal
  - Unused paraldehyde in the community must be returned to the dispensing pharmacy.
  - It must be treated as a hazardous substance and must be placed in a pharmaceutical hazardous waste container and disposed of correctly.
  - COSHH advice should be sought for spillages, or use local guidelines.

7. Dosing and administration

- Refer to a specialist prescriber for the usual dosing regimes.
- Do not repeat unless explicitly authorised by the prescriber.
- Put patient into the left lateral (recovery) position.
- Use personal protective equipment (PPE) as outlined in the COSHH risk assessment.
- Draw up immediately before use and use within 10 minutes, as paraldehyde degrades plastic.
- Paraldehyde can typically be drawn up directly via either a quill (a soft rectal tube) or a rubber bung, depending on local policy.
- Use an appropriately sized syringe and quill; see Figure 2 for examples.

Figure 2: Examples of paraldehyde syringes and quills

- Lubricate the tip with a water-based lubricant and insert quill approximately 2cm without using force. The length of insertion should be advised by the prescriber.
- Administer slowly.
- Gently remove quill and hold the patient's buttocks together for 1–2 minutes to make sure the solution does not leak out.
- Dispose of syringes as per local policy. They (and any contents) must not go into normal household waste or be tipped down the sink/toilet. Paraldehyde is highly hazardous. If medication remains in the bottle it should be returned to the dispensing pharmacy.
- Wash hands thoroughly with soap and hot water.

8. Aftercare and monitoring

- Follow the individual's emergency protocol.
- Call emergency services if seizures persist beyond the care plan limits, breathing is impaired or the person remains unresponsive.
- Inspect perianal skin for irritation or soreness.
- Document dose, time, effect and any adverse reaction.
- The patient's breath will smell of paraldehyde for some hours after it has been given. This is nothing to be concerned about.

9. Safety notes for trainers

- Emphasise the need for dignity and privacy.
- A manual handling risk assessment may be needed if lifting is required.
- Avoid over-insertion of the quill device.
- COSHH precautions should be followed due to the chemical risk.

10. Training and competency

Training must be delivered by a competent healthcare professional with expertise in seizure management and COSHH safety. Rectal administration is a specialist module requiring defined competencies, supervision and two-yearly face-to-face refresher training in line with ESNA best practice guidelines.

11. Interface with emergency services

Local ambulance service policies may differ; the individual's protocol should specify wording for speaking to 999 call handlers and escalation criteria.

12. Documentation and audit

Record dose, time, batch number, effect and any adverse events in the person's notes and the incident report. Each use should be reviewed at MDT meetings and the protocol revalidated.

13. Sources of information

Useful sources of further information are:

- Paraldehyde (BNF for Children, undated)
- The Epilepsy Prescriber's Guide to Antiepileptic Drugs (Patsalos and St Louis, 2018)
- Safety data sheet: Paraldehyde (Sigma-Aldrich, 2026)
- Safety data sheet: Paraldehyde 50% in olive oil rectal solution (Huddersfield Pharmacy Specials, 2016)
- Paraldehyde (rectal) for stopping seizures (Medicines for Children, 2014)
- Paraldehyde and olive oil enema (GOSH, undated)

14. Disclaimer

This appendix has been produced with expert input and reflects current UK practice. There is limited published guidance on paraldehyde administration in adults; recommendations are based on expert consensus and ESNA Review Committee experience. While every effort has been made to ensure accuracy, ESNA and the Review Committee accept no responsibility for errors or omissions.

COSHH risk assessment: Risk checklist

Note: This checklist sets out what to consider in a COSHH risk assessment, but is not necessarily an exclusive list.

Rectal paraldehyde (use and administration)

- Associated document: Appendix VI: Rectal paraldehyde (specialist, exceptional use)
- Setting: Community/residential care/specialist health service
- Assessor: [Name and role]
- Date: [Insert date]
- Review: [Insert review date, maximum two years]

1. Description of activity

Administration of rectal paraldehyde (50:50 paraldehyde and olive oil) in emergency management of prolonged or cluster seizures when first-line medications (e.g. buccal midazolam or rectal diazepam) are ineffective or contraindicated.

2. Persons at risk

This may include:

- the person receiving treatment
- the carer or family member administering the treatment
- bystanders or other residents, and
- pharmacy personnel handling the medication preparation.

3. Hazard identification and controls

Table 5 outlines hazards that may be present in paraldehyde administration, the risks they pose and measures to control them.

Table 5: Identifying paraldehyde risks and control measures

Hazard	Risk	Existing controls and precautions	Further actions (if needed)
Flammability	Fire Burns	Store in glass container, away from heat, sparks or naked flames Do not refrigerate Keep container closed No smoking or open flame in area	Ensure there is local fire safety training Maintain clear 'Highly flammable' signage In case of fire, extinguish with water spray (fog), alcohol-stable foam, dry chemicals or carbon dioxide
Skin irritation	Dermatitis Chemical burns	Wear nitrile gloves and an apron Wash any skin contact immediately with cold running water for 15 minutes If irritation occurs, seek medical advice	Provide COSHH data sheet at point of use
Eye irritation	Chemical burns	Wear eye goggles or face protection If any contact occurs, rinse eyes with water for at least 15 minutes Remove contact lenses, if present and easy to do so If irritation occurs, seek medical attention immediately	Provide COSHH data sheet at point of use Include eyewash access
Inhalation of vapour	Respiratory irritation Dizziness Flammability risk	Use in well-ventilated room Avoid prolonged exposure	Consider spill kit or ventilation fan if confined space
Ingestion/ accidental exposure	Toxicity Organ damage	Paraldehyde is clearly labelled 'Not for ingestion' Secure storage, not accessible to patients/public	Store in locked medicine cupboard in line with controlled drugs protocol
Decomposition of product	Administration of partly decomposed paraldehyde is highly toxic	Discard if discoloured or smelling of vinegar	Regularly check expiry and batch numbers Dispose of appropriately as a hazardous substance, in line with local policy
Incompatibility with plastics	Leaking syringe Degraded material	Draw up immediately before use Use glass where possible Discard if left in syringe for more than 15 minutes	Provide single-use syringes and quills in kit

Manual handling and positioning	Back injury to staff Discomfort to patient	Manual handling training Second staff member for support Use recovery (left lateral) position	Record individualised manual handling plan in care documentation
Dignity and safeguarding	Psychological distress	Close door/curtain Administration by same-sex carer if possible Explain procedure	Include consent and best-interests documentation
Waste disposal	Environmental contamination Injury	Dispose of syringes, gloves and materials as hazardous waste, in line with local policy Do not put down the sink or toilet Return residual medicine to pharmacy	Audit waste management compliance

4. Training and competence

- Only trained, assessed staff may administer rectal paraldehyde.
- A mandatory two-yearly refresher course in seizure management is required under ESNA best practice guidelines and COSHH regulations.
- Staff competence should be recorded on the local training matrix.

5. Monitoring and review

- Review practice following any incident, near miss or product change.
- Include paraldehyde in MDT review of individual emergency care plan.
- Annual audit of documentation and storage arrangements.

6. Sign-off

Name Role Signature Date

Appendix VII: Example buccal midazolam emergency care plan

Version:_____ Review date: _____ Page: _____ of _____

Patient information

Name	
Date of birth	
Known allergies	
NHS number (if applicable)	
Address/service location	

Description of seizures requiring buccal midazolam

	Seizure description
1.	
Usual duration	
2.	
Usual duration	
3.	
Usual duration	
Other useful information	

Midazolam treatment plan

When should buccal midazolam be administered?	
Initial dosage / prescribing weight	
Typical reaction(s) to midazolam	
Action to take if difficulties occur during administration (e.g. excessive salivation)	
Can a second dose be given? ☐ Yes ☐ No (If Yes, include in multidisciplinary plan and call 999 if administered)	

When should 999 be called for emergency help? e.g. if: ☐ Seizure continues after _____ minutes ☐ other concerns	
Maximum 24-hour dose limit	
Recording and governance notes – all administrations must be recorded in clinical records	

Signed by

Prescriber / epilepsy specialist	Signature and date:
Patient / representative (e.g. family member or care manager)	Signature and date:
Care plan author / trainer	Signature and date:
Next review date	Signature and date:

This template has been produced by the Epilepsy Specialist Nurses Association (ESNA). It may be co-branded by local providers but must retain the ESNA logo and reference to ESNA's Best practice guidelines for professional carers in emergency seizure medication: Training standards for the safe administration of buccal (oromucosal) midazolam in the community (2026).

Appendix VIII: Example training evaluation feedback form

Evaluation form for basic epilepsy course: buccal midazolam and/or rectal diazepam

Date of course:	**Trainers:**

Please tick √ **one** of the appropriate boxes for each question.

1. Was the course content relevant to you?

☐ Of limited relevance ☐ Of some relevance ☐ Highly relevant

Comments:

.....

.....

.....

2. Did the overall presentation and delivery of the training meet your needs?

☐ Met only a few ☐ Met some ☐ Met most or all

Comments:

.....

.....

.....

3. Having completed the course, do you feel confident to administer buccal midazolam?

☐ No ☐ Not sure ☐ Yes

Comments:

.....

.....

.....

4. Having completed the course, do you feel confident to administer rectal diazepam?

☐ No ☐ Not sure ☐ Yes

Comments:

.....

.....

.....

5. Would you recommend this course to others?

☐ No ☐ With some explanation ☐ Yes

6. Were the training facilities appropriate, i.e. venue, visual aids etc?

☐ Unsatisfactory ☐ Satisfactory ☐ Good

Comments:

.....

.....

.....

7. Is there any other information that you would like to be included in the training programme?

☐ Yes ☐ No

Comments / suggestions:

.....

.....

.....

8. Will you use this epilepsy course towards a qualification?

☐ Yes ☐ No

If yes, please give details e.g. RQF/NVQ in health and social care, other care training standards:

.....

.....

.....

Thank you for completing this form.

Source: This example of a training evaluation feedback form – amended for use by other trainers – was provided by community epilepsy specialist nurse Christine Cole, who contributed to the guidelines as a clinical member of the Review Committee. It draws on her experience in developing an education programme for social care staff working with people with a learning disability and epilepsy (Pointu and Cole, 2005).

Appendix IX: Contributors and acknowledgements

This appendix lists the contributors, reviewers and advisors who participated in the development of the 2026 ESNA midazolam training guidelines. It recognises the broad expertise and collaboration that supported this third edition, reflecting contributions from clinical, educational, organisational and charitable sectors across the UK and Ireland.

Review lead and lead authors

(Listed alphabetically by surname following the review lead)

The following section outlines the review lead and lead authors responsible for developing and overseeing these best practice guidelines. Each member brings extensive clinical expertise and leadership experience in epilepsy care, education and training.

- **Caryn Jory RGN, RSCN, Queen's Nurse, NMP (review lead)**

  Lead Epilepsy Specialist Nurse and Vice Chair, ESNA

  Caryn has been an adult and children's trained nurse specialising in epilepsy and learning disabilities for over 16 years. She is the co-author of multiple peer-reviewed papers on epilepsy training in community settings and an experienced epilepsy trainer for families and care staff. Caryn is the former registered manager of a specialist care home for adults with complex epilepsy, and has additional experience commissioning epilepsy training. She was the lead author on the previous two reviews of these best practice guidelines.

- **Deborah Coker RNLD, BSc (Hons), NMP**

  Lead Epilepsy Specialist Nurse and Secretary, ESNA

  Deborah is a learning disabilities nurse with over 25 years' experience in managing the holistic care of people with epilepsy in acute hospital settings. She is skilled in developing and implementing emergency care plans and has been delivering epilepsy and emergency medication training for care staff across settings for more than 30 years. Deborah is dedicated to improving understanding and standards of epilepsy care.

- **Sally-Ann Remnant RNLD, BSc (Hons), MSc Epileptology, NMP**

  Epilepsy Specialist Nurse, University Hospitals Sussex NHS Foundation Trust (Brighton)

  Sally-Ann has been a clinical nurse specialist in epilepsy since 1997, with experience across community, primary and secondary care. She was previously an advanced nurse practitioner in epilepsy at Guy's & St Thomas' NHS Foundation Trust and clinical nurse specialist at King's College Hospital NHS Foundation Trust. Sally-Ann is a qualified clinical trainer (ENB 998) and private nurse consultant with the training provider Epilepsy Explained. She has contributed to research and previous reviews of the buccal midazolam guidelines and is an ESNA Executive member.

- **Fiona Short RN (Child), RSN, BA (Hons), PGDip SCPHN, PGCE, NMP**

  Manchester University NHS Foundation Trust, ESNA Executive member

  Fiona is a specialist in paediatric and young people's epilepsy, particularly complex and difficult-to-treat cases. She leads transition services from paediatric to adult care and delivers epilepsy and rescue medication training to schools, families, professionals and carers. She has previous experience as a youth health nurse and lecturer in health and social care within the further education sector.

Core Best Practice Revision Group

The Core Best Practice Revision Group met monthly from March 2025 to March 2026. In between these meetings the group provided detailed editorial input, literature review and drafting support for this third edition of the best practice guidelines. Members represented a balance of clinical, educational and charitable sector expertise, ensuring that the guidelines reflect a broad and inclusive professional consensus.

(Listed alphabetically by surname)

- **Shelley Anderton RNLD, Msc Epilepsy Practice, BSc (Hons) Epilepsy Care, NMP (epilepsy)**

  Epilepsy Specialist Nurse Lead (Adults), East Suffolk and North Essex NHS Foundation Trust

  Shelley has over two decades of experience in epilepsy care and training. She began teaching midazolam administration in 2001 and continues to deliver specialist education both in her NHS role and independently. Her insight into adult community practice was integral to aligning the guidelines with real-world clinical delivery.

- **Jo Campbell RN Adult and Children, independent prescriber, MSc Advanced Nursing Practice**

  Roald Dahl Children's Epilepsy Nurse Specialist

  Jo is an experienced paediatric epilepsy nurse specialist and independent prescriber, with over 20 years in specialist nursing roles and 25 years of teaching experience in epilepsy awareness and emergency medication. Her clinical expertise supports the development of safe, evidence-based training standards for children's services.

- **Elaine Cowan**

  Practice Development Nurse, The William Quarrier Scottish Epilepsy Centre

  Fiona is based at The William Quarrier Scottish Epilepsy Centre, is a 12-bed epilepsy assessment unit based in Glasgow, where she delivers a three-day epilepsy train-the-trainer course. Fiona was involved with the review process to share the centre's knowledge and experience and support the ESNA guidelines.

- **Edel Curran**

  Training and Quality Manager, Epilepsy Ireland

  With over 20 years' experience in the non-profit sector, Edel has led national training programmes in epilepsy awareness and buccal midazolam administration since 2018. She holds a BA (Hons) in applied social studies in social care and is a qualified train-the-trainer. Edel represented Ireland in this review, contributing expertise on cross-border training standards and governance.

- **Alan Foster**

  Managing Director, Essential 6 Ltd

  Alan is the managing director of Essential 6 Ltd, a UK-based company providing first aid and safety training to organisations. An award-winning entrepreneur and former Royal Navy professional, he has led his team in delivering training to over 700 organisations nationally. Alan brought strategic insight and practical experience in large-scale workforce development and training governance.

- **Alison Fuller**

  Director for Health Improvement and Influencing, Epilepsy Action

  A registered nurse by background, Alison leads Epilepsy Action's national health improvement and influencing work. She brought extensive experience in patient safety, quality improvement and clinical governance to the review, and is committed to raising the profile of epilepsy and improving outcomes through collaboration between professional bodies and the voluntary sector.

- **Pollyanna Kellett**

  Lecturer in adult nursing

  Pollyanna specialises in medication safety and resilience in nursing practice. Her published research includes a 2015 review on double-checking high-risk medications and a 2024 BMJ Open Quality paper on nurse and system resilience. She provided academic oversight on medication safety and human factors in training.

- **Fiona Kettell**

  Operations Manager, Epilepsy Wales

  A registered nurse with over 40 years' experience, Fiona has worked in the third sector for two decades, supporting individuals and families affected by epilepsy. As Operations Manager for Epilepsy Wales, she delivers extensive epilepsy and buccal midazolam training to health and social care staff and families, as well as in educational settings, drawing on both professional and lived experience.

- **Dr Michael Loizou**

  Associate Professor and Co-Director, University of Plymouth Centre for Health Technology

  Michael has substantial experience in the area of digital health, especially for mental health and neurodiversity. He consulted on AI oversight for this report.

  He has leadership experience, serving as visiting professor and fellow in multiple institutions, journal editorial roles, advisory roles to health bodies (NHS Digital, Health Education England and the Royal College of Psychiatrists) and leading/co-leading national projects for the National Institute for Health and Care Research (NIHR) and Engineering and Physical Sciences Research Council (EPSRC).

- **Andree Mayne**

  Education, Information and Support Services Manager, Epilepsy Society

  Andree has supported people with epilepsy and associated conditions for over 15 years. She leads the development and delivery of educational and support services for the Epilepsy Society, focusing on promoting understanding and wellbeing through accessible information and professional education.

- **Kirsten McHale MSc, BSc (Hons)**

  Epilepsy Nurse Consultant, Young Epilepsy

  Kirsten has supported children and young people with complex epilepsy for over 20 years within both the NHS and charitable sectors.

- **Maisie Meegan**

  Engagement Coordinator, Epilepsy Action

  Maisie leads professional engagement and training initiatives at Epilepsy Action, building relationships with healthcare professionals and supporting the dissemination of best practice. Her work focuses on improving the accessibility and inclusivity of epilepsy education and training resources.

- **Lisa Obrien**

  Former Head of Health and Wellbeing and Epilepsy Specialist Nurse, The Meath Epilepsy Charity

  Lisa has been a qualified nurse for more than 30 years, specialising in neurology, brain injury and complex needs. She has focused on epilepsy for over 20 years, working in the NHS, private sector and charities. Lisa delivers training in epilepsy awareness and emergency medication to multiple agencies. She has previously worked at Young Epilepsy as its epilepsy nurse consultant and at The Meath supported adults with epilepsy and complex health needs. Lisa has been involved in previous reviews of the best practice guidelines.

- **Simon Privett**

  Learning and Training Lead, Epilepsy Action

  With nearly 30 years of lived experience of epilepsy, Simon combines personal insight with professional training expertise. At Epilepsy Action, he leads education programmes for corporate and community audiences, promoting understanding of and inclusion in epilepsy care.

Review Committee (wider consultation group)

The Review Committee included clinicians, educators and organisational representatives from across the UK and Ireland. Members provided specialist feedback and consensus input through structured consultation and review, ensuring the guidelines reflect diverse expertise and current best practice.

(Listed alphabetically by surname within specialisms)

Clinical members

The following clinicians contributed expert review and practical insight, representing a broad spectrum of epilepsy care across acute, community and specialist services.

- **Carys Amies RN (Child), SCPHN, independent prescriber, DipHE, BSc**

  Senior children's epilepsy nurse specialist, Hull

  Carys has 11 years' experience as a children's epilepsy nurse specialist, providing training and support to schools, nurseries and community providers. Her expertise ensured the inclusion of practical guidance for paediatric and education sector staff in development of the guidelines.

- **Rebecca Boxall BSc (Hons) Nursing (Learning Disabilities)**

  Children's Epilepsy Nurse Specialist, Portsmouth Hospitals University NHS Trust

  Rebecca has a background in learning disability and paediatric epilepsy nursing. She has experience drawn from both specialist school and NHS roles, contributing to guidance on care planning and training in educational and community settings.

- **Emma Christie**

  Epilepsy specialist nurse, Somerset NHS Foundation Trust

  Emma is a children's epilepsy nurse at Yeovil Hospital, where she set up a new epilepsy service in 2022, and delivers midazolam training to families, nurseries, schools and colleges. She had a particular interest in developing the guidelines to ensure clinical governance, consistency and equity in training delivery standards.

- **Christine Cole MBE, RNLD, BA, MSc (Epileptology), NMP, QN**

  Community epilepsy specialist nurse, London North West University Healthcare NHS Trust

  Christine has over 25 years' experience as a community epilepsy nurse, specialising in learning disability and general population services. She has been recognised with an MBE for her contribution to epilepsy care and brought deep expertise in community training and governance.

- **Keri John**

  Epilepsy specialist nurse, Cardiff and Vale University Health Board

  Keri is an experienced registered nurse with nearly four decades of clinical practice, including 19 years as an epilepsy specialist nurse. Her focus is on holistic care, recognising the psychosocial impact of epilepsy and the importance of education in improving quality of life.

- **Sarah Kerley**

  Epilepsy specialist nurse

  Sarah is an experienced ESN providing care and training within multidisciplinary teams. Her input supported the refinement of the guideline's competency framework and alignment with ESNA's clinical standards.

- **Jenny Piedot RNMH, BA (Hons) Ed, PGCert (Epilepsy), NMP**

  Epilepsy specialist nurse, Torbay and South Devon NHS Foundation Trust

  Jenny works as an ESN with extensive experience in adult learning disability services. She contributes to clinical education, patient support and best practice implementation across community settings.

- **Jay Price RNLD**

  Epilepsy specialist nurse, Dorset HealthCare University NHS Foundation Trust

  Jay has a specialist interest in epilepsy in people with learning disabilities. In her role with the Dorset HealthCare University trust she is the community learning disability nurse for Bournemouth, Christchurch and Poole.

  Jay has worked with people with learning disabilities and epilepsy both professionally and privately. She is the epilepsy champion for her team and delivers epilepsy awareness and buccal midazolam training to Dorset care providers and healthcare professionals.

- **Marion Saunders**

  Epilepsy specialist nurse

  Marion is an experienced ESN providing clinical care and education for people with epilepsy in community and acute settings. She contributed expert review input to ensure alignment of training standards with everyday clinical practice.

Education and training specialists

These members contributed expertise in workforce education, curriculum design, quality assurance and practical training delivery. Their collective experience across the NHS, education and independent training sectors ensured that the guidelines' competency and delivery standards are educationally robust, realistic and aligned with national frameworks.

- **Nicola Fielding**

  Lecturer in children's nursing, University of Plymouth

  Nicola's clinical background is in children's palliative and complex care. Her academic interests centre on advancing education and practice to enhance the quality of care for children with life-limiting and complex conditions.

- **Sarah Gibson RGN, PGCert (Epilepsy Studies)**

  Senior Clinical Skills Facilitator, Mersey Care NHS Foundation Trust

  Sarah leads epilepsy awareness and emergency medication education for health and social care professionals. Her experience in reviewing and improving organisational training provision directly informed the guidelines' standards for course duration, delivery and trainer competence.

- **Denise Kindleysides**

  Dual-registered adult and children's nurse, nurse educator

  Denise is a dual-qualified nurse with extensive experience across acute, community and specialist care. She has developed and delivered education programmes for multidisciplinary teams, focusing on translating clinical evidence into safe and effective practice. Her expertise in teaching and mentorship informed the structure and content of the guidelines' training and competency framework.

- **Samantha Loosley**

  Health and social care trainer, Independence Matters

  Samantha delivers health and social care training to support staff who work with people with learning disabilities, autism and physical disabilities. Her practical insight into workforce learning needs helped shape the guidelines' emphasis on accessibility, reflection and inclusive learning approaches.

- **Nicola Milne BSc (Hons) Psychology, SVQ 4 Health & Social Care**

  Training Manager, Capital Care Training

  Nicola has over 20 years' experience in health and social care education, including 14 years in the epilepsy charity sector. She specialises in the delivery of epilepsy and rescue medication training for community-based care teams, schools and local authorities. Nicola contributed to the development of the guidelines' modular training framework and quality assurance processes.

- **Tara Smith**

  Director of Services, Epilepsy Ireland

  Tara has over 25 years' senior management experience in the non-profit sector in Ireland, including seven years with Epilepsy Ireland, the National Patient Organisation in Ireland where she works alongside colleagues to ensure a society where no person's life is limited by epilepsy. Tara supports the Epilepsy Ireland training and community resource officer teams who deliver training to education and healthcare professionals across Ireland.

- **AJ Stewart**

  Educationalist, qualification developer and quality assurance specialist

  AJ is an experienced educationalist and qualification designer with a background in nursing, resuscitation and clinical skills education. He has led the design and quality assurance of national qualifications within health and social care and advises on compliance and evidence-based workforce development. His input ensured the guidelines' educational standards align with recognised qualification frameworks.

Organisational and technical advisors

This section acknowledges contributors who provided expertise from the perspectives of care provision and digital innovation. Their insights supported the practical implementation and technological integrity of the guideline development process.

- **Dr Amir Ali**

  Lecturer in Artificial Intelligence and Robotics, University of Plymouth

  Amir is a lecturer at the University of Plymouth and leads its MSc Artificial Intelligence programme. He is also Vice Chair of the Institute of Electrical and Electronics Engineers (IEEE) UK and Ireland Robotics and Autonomous Systems (RAS) Chapter. His research focuses on artificial intelligence (AI) applications in healthcare, particularly in the diagnosis of neurodevelopmental disorders such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) and neurological disorders such as epilepsy (including SUDEP risk stratification), as well as diseases such as Alzheimer's and tuberculosis. Amir specialises in multimodal data – spanning speech, imaging and biological markers – and develops explainable machine learning models that support early diagnosis and clinical decision-making. He works closely with the NHS and industry partners and supervises a wide range of translational projects at the intersection of AI and healthcare.

- **Jonathan Steed**

  Director of Care, Bowden Derra Park Ltd

  Jonathan has worked with people with learning disabilities and complex needs, including epilepsy, for over 30 years. He has contributed to national and international research projects and brings a deep understanding of operational realities in specialist care. His experience in both delivering and commissioning epilepsy training provided valuable input on the applicability of standards within care provider settings.

Advisors for paraldehyde guidelines (Appendix VI)

- **Mathew Garrod**

  Lead Neurosciences Pharmacist and Specialist Pharmacist in Migraine, University Hospital Southampton NHS Foundation Trust

  With over 15 years of NHS experience, Mathew is nationally recognised for leadership in neurology pharmacy, clinical education and service transformation. He lectures at several universities, supports postgraduate training and has co-authored tools, guidelines and resources to advance evidence-based care.

- **Sabrina Tierney**

  Paediatric Pharmacist, Royal Cornwall Hospitals NHS Trust

  Sabrina is the lead pharmacist for paediatrics and women's health at Royal Cornwall Hospitals NHS Trust. She also works with Little Harbour, a paediatric hospice in St Austell that is part of the Children's Hospice South West charity.

Advisor for midazolam guidelines

- **Professor Rohit Shankar MBE, FRCPsych**

  Professor in Neuropsychiatry, Cornwall Intellectual Equitable Research (CIDER), University of Plymouth, Peninsula School of Medicine

  Rohit is an internationally recognised leader in the field of epilepsy and neuropsychiatry. He is Vice Chair of the Royal College of Psychiatrists' Faculty of the Psychiatry of Intellectual Disability and a Consultant in Adult Developmental Neuropsychiatry at Cornwall Partnership NHS Foundation Trust.

  He is also Clinical Director of Adult Learning Disability Services.

  His research focuses on improving safety, quality of life and health outcomes for people with epilepsy and learning disabilities. He has provided expert oversight and strategic guidance to the review process, ensuring the guidelines reflect current clinical evidence and best practice across community and specialist care.

For further information please contact ESNA (https://esna-online.org/)

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