



[REDACTED]  
[REDACTED]  
Nursing and Midwifery Council  
Portland Place  
London  
W1B 1PZ

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[REDACTED]  
[REDACTED]  
[REDACTED]  
Thursday 17<sup>th</sup> October 2024

**Re: EpilepSy Nurse Association guidelines and the NMC Code**

Dear [REDACTED]

I am the Director of ESC Management Services, a company that works with organisations to strengthen arrangements for health provision within educational settings. I have previously had communication with Professor Geraldine Walters at the NMC in relation to delegation.

I am contacting you about the EpilepSy Nurses Association (ESNA) best practice guidelines for training professional carers in the administration of buccal midazolam.<sup>1</sup> The 2023 version is the second edition, with the first edition issued in 2019. In the updated 2023 edition, there is an explicit reference to the document being compliant with the NMC 'code of conduct' (pg. 2), which I have taken to mean the NMC Code. However, on the face of it, aspects of these guidelines appear to conflict with the Code's standards. Therefore, I am seeking clarification on whether the NMC considers these ESNA guidelines to be compliant, as stated in the document.

In summary, the guidelines are positioned to cover a range of community settings for children, young people and adults with epilepsy who require the administration of buccal midazolam to treat seizures. The section that sets out 'training' standards identifies four groups of 'Trainer Competencies'. The descriptions of the trainers in the four groups are set out below.

**Group 1:** Those who educate people with epilepsy and their carers about epilepsy and safe administration of buccal midazolam for example: within a clinic, ward or home visit setting.

**Group 2:** Those who teach caregivers epilepsy awareness and the safe administration of buccal midazolam outside a clinic, ward, or home visit setting: for example, teaching at external organisations such as to care home staff, day services, social care organisations.

**Group 3:** Those who provide epilepsy and buccal midazolam training as a 'Train the Trainer' (TTT).

**Group 4:** Paid health or support workers who have completed an appropriate TTT course – Epilepsy and the safe administration of buccal midazolam and who then intend to teach other caregivers within their organisation only.

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<sup>1</sup> ESNA (2023) Interim best practice guidelines for training professional carers in the administration of buccal (oromucosal) midazolam for the treatment of prolonged and/or clusters of epileptic seizures in the community [https://esna-online.org/wp-content/uploads/2024/01/Midazolam-interim-guidelines-MI\\_12454014\\_21.12.23\\_V\\_3.pdf](https://esna-online.org/wp-content/uploads/2024/01/Midazolam-interim-guidelines-MI_12454014_21.12.23_V_3.pdf)



Groups 1-3 description of competencies start with *'Must have a nursing or medical qualification'*. Therefore, presumably, the intention is that NMC registrants will have a role in this approach advocated by the ESNA. The approach covers direct 'training' to administer buccal midazolam for carers and paid support workers and also 'training' health and care workers to train others in their organisation to administer buccal midazolam i.e. a Train the Trainer model.

In light of the NMC Code and also the NMC's supplementary information on delegation and accountability, four main concerns and issues about the guidelines are outlined below.

1. Children, young people and adults should have a written care plan setting out the personalised care and treatment required.<sup>2,3</sup> In many areas, this is likely to involve specialist epilepsy services/nurses planning and overseeing care in line with CQC and NMC regulatory requirements. This should cover the delegation of healthcare activities set out in the plan such as administering medication to treat seizures. However, the ESNA guidelines are framed around 'training' and refer to the life support training model. It is my understanding that administering buccal midazolam on a named basis would not be considered first aid.<sup>4</sup> Framing this as stand-alone 'training' seemingly has the effect of side-stepping the NMC standards and requirements (see point 3). Certainly, for Groups 1 and 2, if this involves an NMC registrant, it appears these activities would/should fall within the scope of delegation under the NMC Code Standard 11.
2. There are questions about the legality of the ESNA approach, specifically around children and young people in community settings. The statutory schemes that cover health, social care and education differ and this includes the statutory provisions for the delegation of healthcare activities. Therefore, what may be compliant in one setting may not be compliant in another. Consequently, it would be inappropriate to apply a blanket approach to transferring responsibility for administering buccal midazolam to support workers across a range of community settings with no limits or acknowledgement of the different statutory schemes. Yet, this is what the ESNA guidelines do. Potentially, this may expose NMC registrants to risks concerning the Code Standard 20.4.
3. The ESNA guidelines place the responsibility for assessing competency on the support worker's employer e.g. a social care service provider. Under the guidelines, the 'trainers' which may be NMC registrants, appear to be absolved of a requirement to confirm competence in the task. Whilst I acknowledge assessing competency in the administration of buccal midazolam presents challenges, it is accepted practice for services/registered health professionals to use simulated scenarios to undertake practical assessments. So, practical competency assessments are possible and seem to be a requirement of NMC compliant delegation.
4. There are also questions about NMC registrants' involvement in a Train the Trainer model to deliver healthcare to individuals on a named basis (service-user and support worker/s). In the ESNA approach, NMC registrants may have unregistered support workers acting as a proxy in 'training' others to provide care. In these arrangements, NMC registrants

<sup>2</sup> NICE (2022) Guideline [217] Epilepsies in children, young people and adults <https://www.nice.org.uk/guidance/ng217>

<sup>3</sup> NICE (2023) Quality Standard [QS211] Epilepsies in children, young people and adults <https://www.nice.org.uk/guidance/qs211>

<sup>4</sup> HSE (Reissued 2018) The Health and Safety (First-Aid) Regulations 1981 pg. 17 <https://www.hse.gov.uk/pubns/priced/l174.pdf>



delivering 'training' would be removed from direct contact with the support worker providing care and the service user receiving care, so who would be responsible for oversight and monitoring of this aspect of care?

These concerns/issues are being raised because the ESNA guidelines are increasingly being presented as an authoritative resource and an approach that should be adopted for a range of support workers, including teaching assistants in schools and passenger assistants on school transport. These workers often have no prior medical/health care training or experience and minimal/no clinical governance frameworks within their employing organisation. All this is in the context of midazolam being a controlled drug with serious side effects/complications.

I am also mindful that in recent years, there has been a lengthy process of consultation and legislation changes to remove restrictions on paramedics administering midazolam.<sup>5,6</sup> This process provided an opportunity for thorough consideration, including stakeholder engagement.<sup>7</sup> To my knowledge, there have been no relevant proposals or changes to legislation around support workers administering midazolam in community settings.

My concern is that the ESNA guidelines are serving to circumvent the legislative, regulatory and governance requirements that are in place to ensure/assure quality for this aspect of care in community settings. Therefore, I would be grateful if you could consider the points raised and provide clarification on whether the ESNA guidelines are indeed compliant with the NMC Code, as the ESNA claims.

As a final point, the 2019 version of the ESNA guidelines referred to a peer review process and engaging with the RCN.<sup>8</sup> In 2023, I requested clarification from the RCN, and it was confirmed that the RCN had not endorsed the guidelines and there had been no application submitted to do so.

Yours sincerely,

Emma Smith

Email: [emma@escmanagementservices.co.uk](mailto:emma@escmanagementservices.co.uk)

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<sup>5</sup> NHS England (2020) Consultation on proposed amendments to the list of medicines that paramedics are able to administer under exemptions within the Human Medicines Regulations 2012 across the United Kingdom <https://www.england.nhs.uk/wp-content/uploads/2020/10/paramedic-full-consultation.pdf>

<sup>6</sup> Home Office (2023) Circular 007/2023: the Misuse of Drugs (England and Wales and Scotland (Amendment) (No.2) Regulations 2023 <https://www.gov.uk/government/publications/circular-0072023-the-misuse-of-drugs-no2-regulations-2023/circular-0072023-the-misuse-of-drugs-england-and-wales-and-scotland-amendment-no2-regulations-2023>

<sup>7</sup> Health and Care Professions Council (2020) Response to NHS England's consultation on proposed amendments to the list of medicines that paramedics are able to administer under exemptions within the Human Medicines Regulations 2012 across the United Kingdom <https://www.hcpc-uk.org/globalassets/resources/external-consultations/2020/hcpc-response-to-consultation-on-medical-entitlements-for-paramedics.pdf?v=637471748810000000>

<sup>8</sup> ESNA (2019) Best practice guidelines for training professional carers in the administration of buccal (oromucosal) midazolam for the treatment of prolonged and/or clusters of epileptic seizures in the community pg. 13 <https://ilaebritish.org.uk/content/uploads/2019/06/ESNA-Midazolam-Guidelines.pdf>