

The Role of the Advanced Nurse Practitioner in Deep Brain Stimulation Therapy for Movement Disorders

Rola pielęgniarki zaawansowanej praktyki w terapii głęboką stymulacją mózgu u pacjentów z zaburzeniami ruchowymi

Sarah Perides¹, Joseph Candelario-Mckeown²

① Children's Neurosciences, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust, London, United Kingdom

② Unit of Functional Neurosurgery, National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust, London, United Kingdom

Abstract

Deep brain stimulation has been used in the treatment of movement disorders for more than 30 years. Most published literature focuses on surgical techniques, therapeutic paradigms, and clinical outcomes, whereas less attention has been paid to the multidisciplinary roles required to deliver a deep brain stimulation service and their impact on treatment success. This review examines the role of the Deep Brain Stimulation Clinical Nurse Specialist and Advanced Nurse Practitioner and their contribution to patient experience and clinical outcomes. The article provides an overview of the relationship between the Deep Brain Stimulation Clinical Nurse Specialist/Advanced Nurse Practitioner and the patient, from initial selection, through surgery and postoperative recovery, to long-term follow-up. It also discusses the involvement of these nurses at each stage of care and their role in coordination, education, support, and therapy management. The roles of the Deep Brain Stimulation Clinical Nurse Specialist and Advanced Nurse Practitioner are evolving and require advanced clinical expertise, autonomous practice, research involvement, education, and patient advocacy. These roles are essential within the multidisciplinary team and may contribute to improved patient care and outcomes. (JNNN 2026;15(1):29–35)

Key Words: advanced nurse practitioner, clinical nurse specialist, deep brain stimulation, movement disorders

Streszczenie

Głęboka stymulacja mózgu jest stosowana w leczeniu zaburzeń ruchowych od ponad 30 lat. Większość opublikowanej literatury koncentruje się na technikach chirurgicznych, paradygmatach terapeutycznych i wynikach klinicznych, natomiast mniej uwagi poświęcono interdyscyplinarnym rolom niezbędnym do świadczenia usług głębokiej stymulacji mózgu i ich wpływowi na sukces leczenia. Niniejszy przegląd analizuje rolę pielęgniarki specjalistki ds. głębokiej stymulacji mózgu i pielęgniarki zaawansowanej oraz ich wkład w doświadczenia pacjenta i wyniki kliniczne. Artykuł przedstawia przegląd relacji między pielęgniarką specjalistką ds. głębokiej stymulacji mózgu/pielęgniarką zaawansowaną, a pacjentem, od wstępnej selekcji, poprzez zabieg chirurgiczny i rekonwalescencję pooperacyjną, aż po długoterminową obserwację. Omawia również zaangażowanie tych pielęgniarek na każdym etapie opieki oraz ich rolę w koordynacji, edukacji, wsparciu i zarządzaniu terapią. Role pielęgniarki specjalistki ds. głębokiej stymulacji mózgu oraz pielęgniarki zaawansowanej ewoluują i wymagają zaawansowanej wiedzy klinicznej, samodzielnej praktyki, zaangażowania w badania, edukacji i wspierania pacjentów. Role te są niezbędne w zespole interdyscyplinarnym i mogą przyczynić się do poprawy opieki nad pacjentem i poprawy wyników leczenia. (PNN 2026;15(1):29–35)

Słowa kluczowe: pielęgniarka zaawansowana, pielęgniarka specjalistka, głęboka stymulacja mózgu, zaburzenia ruchowe

Introduction

Deep brain stimulation (DBS) is a well-established surgical intervention for movement disorders, with more than 30 years of clinical use [1]. Although it is not curative, DBS can significantly improve quality of life in patients with Parkinson's disease [2], dystonia [3], and tremor [4] by modulating abnormal brain activity.

Although DBS is not currently licensed for children under seven years of age with dystonia, emerging evidence supports its safety and efficacy in younger patients [5]. In addition, studies have confirmed a favorable safety profile in older patients with Parkinson's disease, reinforcing DBS as an effective treatment option across a broad age spectrum [6].

As a lifelong therapy, DBS requires comprehensive management of both the progressive neurological condition and device-related factors. The aim is to provide holistic care throughout the entire patient journey, from the selection process to lifelong follow-up, with the involvement of a dedicated multidisciplinary team. Such a team includes neurologists, neurosurgeons, clinical nurse specialists, advanced nurse practitioners, psychologists, psychiatrists, and various therapists [7].

In the United Kingdom, clinical nurse specialists and advanced nurse practitioners play a pivotal role throughout the patient journey. Recognised by the DBS Nurses Association, these nurses possess specialist skills in symptom assessment, adjustment of DBS settings to reduce side effects and improve function, and identification of technical problems [8]. Advanced nurse practitioners may also prescribe medicines independently, thereby supporting the management of complex pharmacological regimens [9].

As the first point of contact for patients and local healthcare providers, clinical nurse specialists and advanced nurse practitioners provide expert advice, coordinate referrals, and deliver comprehensive feedback to the multidisciplinary team, device manufacturers, and, importantly, to patients and their families. Moreover, the *National Toolkit for the Designation of Providers of Deep Brain Stimulation* recommends the appointment of clinical nurse specialist or advanced nurse practitioner roles at all DBS centres, underlining their indispensable contribution to effective DBS management [10].

The aim of this review is to highlight the central role of DBS nurses in the patient pathway, from patient selection to lifelong follow-up care.

Review

Patient Selection

Clinical nurse specialists and advanced nurse practitioners play a critical role in patient selection for DBS. They independently assess patients using standardised clinical tools such as the Movement Disorder Society–Unified Parkinson's Disease Rating Scale, the Fahn–Marsden Dystonia Scale, and the Fahn–Tolosa–Marin Tremor Rating Scale. In addition, they use clinician-administered, disease-specific assessment measures, including patient-reported quality-of-life questionnaires, for example the PDQ-39, and disability scales [8].

In Parkinson's disease, a robust response to levodopa is considered a strong predictor of positive outcomes following DBS [11]. The clinical nurse specialist or advanced nurse practitioner may conduct the levodopa challenge test, which involves assessing motor symptom severity in both the OFF state, after withholding levodopa for six hours before assessment, and the ON state, following the maximum therapeutic response after a single dose of levodopa [12]. In dystonia and tremor, nurses work alongside the multidisciplinary team to evaluate the severity of disability and functional impairment and to establish personalised and realistic surgical goals. Baseline assessments are crucial for comparison with postoperative clinical outcomes [13].

Initial Patient–Clinical Nurse Specialist/Advanced Nurse Practitioner Interaction

Following the initial consultation with the neurologist, patients are often referred to the clinical nurse specialist or advanced nurse practitioner for further clinical assessment. This is typically the first direct interaction between the patient and the DBS nurse. Early engagement with the patient and family is essential for building rapport and establishing trust.

This initial contact provides an important opportunity to discuss the patient's expectations and motivations for undergoing DBS. Nurses are well placed to identify unrealistic expectations, as well as potential red flags such as concentration difficulties, acute confusion, or comorbidities that should be addressed before DBS is considered [14].

During the clinical assessment, it is also important to educate patients about which symptoms and aspects of their condition are likely to improve with DBS and which are unlikely to change [14]. This helps recalibrate expectations towards realistic goals and may reduce dissatisfaction after surgery despite objectively measurable improvement [15]. Early interactions also enable the

nurse to assess the patient's social circumstances, including the availability of support from family members or carers [12].

Furthermore, nurses counsel patients on the possible implications of DBS for employment and on how changes in symptoms and stimulation effects may influence family relationships [16]. Clinical nurse specialists and advanced nurse practitioners can also provide guidance regarding lifestyle adjustments after surgery, for example management of the implanted device battery [14]. The ongoing therapeutic relationship fosters an environment in which patients feel able to discuss their concerns, fears, and hopes openly.

Facilitating Informed Decision-Making

Growing awareness of DBS through social media, the internet, and mainstream media has led to an increase in patient enquiries, particularly following the introduction of adaptive and sensing DBS technologies. Many of these enquiries are directed to clinical nurse specialists and advanced nurse practitioners, underlining their central role within the multidisciplinary team.

These nurses are well positioned to provide accurate and comprehensive information about the patient's DBS journey, surgical risks, life with an implanted device, and the advantages and disadvantages of different DBS systems. Studies have shown that although patient expectations of DBS are often partially met, a considerable proportion of patients still feel inadequately prepared for the procedure [14]. It is therefore important to offer patients opportunities to gain different perspectives on DBS, including contact with individuals who have already undergone the procedure. Clinical nurse specialists and advanced nurse practitioners are ideally placed to facilitate this peer support and to help patients develop a realistic understanding of the surgery and the therapy.

Before surgery, these nurses support both the multidisciplinary team and the patient in determining whether DBS is the appropriate choice, ensuring that realistic expectations have been established and that the long-term implications of living with an implanted device are fully understood. Patients should be thoroughly informed and educated about both the procedure and ongoing therapy before surgery is undertaken.

Clinical Nurse Specialist/Advanced Nurse Practitioner Input During Hospital Admission for DBS Implantation

During the admission for DBS implantation, the nurse plays a pivotal role in optimising both patient safety and the likelihood of a successful procedure.

Hospital admissions for DBS vary in length, from a few days in uncomplicated cases with good expected recovery to several weeks in more complex patients. Often described as the “hub” of the surgical admission, the DBS nurse coordinates multidisciplinary input and ensures that the patient is psychologically and physically prepared for surgery. This includes not only patient education, but also attention to safety and procedural readiness. Key responsibilities include ensuring compliance with infection prevention protocols, reviewing abnormalities in blood test results, and documenting individual surgical preferences, such as the intended device location or hair removal requirements. Compliance with preoperative MRSA suppression therapy should also be checked, as this is important in reducing the risk of postoperative wound infection [17].

Many clinical nurse specialists and advanced nurse practitioners are also confident in attending surgery alongside the neurosurgical team. This enables them to interrogate the implanted pulse generator intraoperatively to confirm correct functioning and to prepare for postoperative programming. The precise location of the DBS electrode within the target structure is crucial to clinical outcome [17]. Knowledge of lead placement can significantly inform later programming decisions, particularly in dystonia, where the response to stimulation may be delayed or where some patients may not be able to describe changes in movement, sensation, or comfort [18].

Recovery Care

Following surgery, family members often seek reassurance and clarity from the clinical nurse specialist or advanced nurse practitioner. The personal and individualised relationship established throughout the patient journey becomes particularly important in the postoperative period [13]. At a time when caregivers and relatives may feel anxious and emotionally vulnerable, even a brief, compassionate conversation may provide significant comfort [19]. Such moments often strengthen trust between the nurse and the family.

The role of the DBS nurse in postoperative care varies depending on the length of hospital stay and the local healthcare setting. Responsibilities may include prescribing postoperative antibiotics, managing wound care, monitoring recovery, and programming or activating the DBS device. Wound care is particularly important, especially in younger patients and in patients with dystonia, who may have an increased risk of wound breakdown, infection, or erosion [20]. Infection prevention and wound-care education therefore form an essential part of postoperative management [21]. In addition, medication adjustments, including temporary

dose changes or management of polypharmacy, may be required to reduce involuntary movements during recovery and to support wound healing.

The nurse's detailed knowledge of the patient's condition, phenotype, and expected recovery trajectory is essential for ensuring a smooth surgical admission and postoperative course. This insight allows care to be tailored to the individual patient and may contribute to improved outcomes.

DBS Programming

DBS programming is one of the core responsibilities of the clinical nurse specialist and advanced nurse practitioner. Programming requires an extensive knowledge of neuroanatomy and neurophysiology, as well as an understanding of musculature and motor function [22]. Nurses must interpret patterns of movement and stillness, identify the mechanisms underlying specific symptoms, and understand how these may be modulated through stimulation. Programming also requires sufficient time to assess the patient's response to stimulation [22]. Patients with Parkinson's disease may require more time than those with dystonia or tremor [22], partly because Parkinson's disease patients often need to be reviewed in the OFF-medication state during assessment. Nevertheless, the DBS nurse must always be prepared to deal with unexpected responses to stimulation.

As DBS is used in the management of several different conditions, therapeutic effects can vary considerably both in magnitude and in time to response. Programming is therefore far more complex than simply switching on an implanted pulse generator. It requires patience, a detailed understanding of stimulation parameters and possible side effects, and careful observation of the individual patient's responses [8].

DBS systems are produced by different manufacturers using different platforms, applications, and modes of stimulation delivery. The DBS nurse must therefore maintain competence across all relevant systems and conditions and seek additional training whenever required [8,13]. The introduction of image-guided programming has further expanded the role, requiring nurses to develop competence in interpreting brain imaging alongside their medical colleagues [23]. Similarly, the emergence of local field potential-based programming has created a steep learning curve in a new clinical concept of DBS management [24]. With the introduction of remote DBS programming, clinical nurse specialists and advanced nurse practitioners are also leading innovations that enable patients to be reviewed and their settings adjusted while remaining in their own homes [25].

Each patient is unique, and stimulation settings must be tailored to the individual condition, phenotype, and response pattern. Only a skilled DBS programmer can integrate all of these elements to optimise treatment, recognise suboptimal outcomes, and provide appropriate support in all clinical circumstances.

Preparing Patients for Hospital Discharge

Hospital discharge following DBS surgery is a critical phase that requires careful coordination and comprehensive education in order to ensure a safe transition from hospital to home.

One important element of discharge preparation is enabling patients to manage their DBS device as independently as possible and to adhere to prescribed medication regimens. This includes education on device operation, compliance with therapy recommendations, and recognition of problems requiring professional review. Patients should also be given clear contact details and explicit instructions about whom to contact in the event of device-related concerns or emergencies.

Another essential component of discharge education is teaching patients to recognise signs of wound complications and infection. Timely follow-up arrangements are also necessary to monitor progress, identify complications early, and optimise therapy outcomes. Effective discharge planning led by the clinical nurse specialist and advanced nurse practitioner promotes patient safety, confidence, and better long-term self-management [19].

These nurses also ensure that all relevant discharge letters and follow-up arrangements are communicated to community healthcare professionals, including local Parkinson's nurse specialists, general practitioners, social services, and, where appropriate, schools.

Educating Patients about Potential DBS-related Side Effects

Patients should be educated about situations that may inadvertently switch off the stimulator, such as electromagnetic interference, and be given practical instructions on how to operate the device, including how to switch stimulation on and off when clinically indicated, how to recharge the implanted pulse generator regularly, and how to monitor for stimulation-related side effects or unwanted symptoms such as weight gain, dyskinesia, balance problems, and behavioural changes [21].

Follow-up Care in Patients with DBS

Clinical nurse specialists and advanced nurse practitioners lead much of the follow-up care for patients with DBS and often run dedicated nurse-led clinics.

Patients are typically seen more frequently during the first year after implantation [13]. In subsequent years, follow-up usually takes place within consultant-led clinics and nurse-led services. Between scheduled visits, interim or urgent assessments may be arranged on an ad hoc basis and are often led by the clinical nurse specialist or advanced nurse practitioner.

These clinics usually include skilled history-taking, detailed medication review, assessment of motor function and muscle tone, DBS programming adjustments, and review of wound healing where relevant. Advanced nurse practitioners may also manage broader multi-system health issues by advising on, or facilitating, referral to other specialties such as gastroenterology, neurourology, psychiatry, psychology, or orthopaedics [9].

Managing Emergencies in DBS

Patients with DBS implants often present with complex healthcare needs and may require input from multiple professionals. Some are also at risk of movement-disorder emergencies. DBS nurses play a key role in monitoring and responding to a wide range of urgent issues, from superficial wound infections to fractured or malfunctioning hardware that may result in acute clinical deterioration.

Management of these situations may involve arranging hospital admission where necessary, coordinating neurological review, facilitating medication assessment, troubleshooting the DBS system, and involving neurosurgeons when revision surgery is required. Early identification of urgent problems and prompt intervention are essential to prevent long-term complications.

In patients who develop behavioural disturbance or sudden cognitive decline related either to DBS settings or medication, the clinical nurse specialist or advanced nurse practitioner may identify the cause and request relevant investigations to exclude acute infection, such as urinary tract infection or chest infection [21]. If stimulation-induced side effects are suspected, the nurse may adjust the DBS settings. Advanced nurse practitioners may also modify medication doses when required. In addition, patients may be referred to psychiatrists, psychologists, or local health providers for longer-term management.

Lifelong care

Adjustment to life after DBS surgery can be transformative, but the pace of improvement varies greatly. For some patients, progress is gradual and emotionally challenging. DBS nurses therefore provide ongoing reassurance and support and emphasise the importance of patience throughout the recovery process [16].

DBS is a lifelong therapy, and most patients continue to have long-term contact with their clinical nurse specialist or advanced nurse practitioner. One important exception is the transition from paediatric DBS care to adult services [26]. In the United Kingdom, only a small number of paediatric DBS centres exist, and when patients reach adulthood they are transferred to adult DBS services for continuing care. This transition is a crucial aspect of management and has improved substantially over the past 15 years due to collaboration among United Kingdom DBS nurses through the DBS Nurse Association. Such cooperation has strengthened continuity of care and supported patients during this particularly challenging period of life. It has also facilitated smoother handovers when adult patients relocate to different regions [26].

Although these transitions are relatively infrequent in the overall United Kingdom DBS population, relationships between patients and their clinical nurse specialist or advanced nurse practitioner are typically long-lasting. Once a DBS device has been implanted, the nurse and neurologist remain responsible for both patient management and device safety [27]. Similar to cardiac pacemakers, DBS implanted pulse generators require specialist management in certain situations, including magnetic resonance imaging, electrocardiography, and diagnostic ultrasound [13]. Patients must also be informed that diathermy and monopolar electrocautery may cause tissue damage and severe injury [21]. They should therefore be advised to contact their clinical nurse specialist or advanced nurse practitioner whenever they require medical investigations or surgical procedures.

Patients should also be educated about safety precautions in everyday life, including situations involving strong magnetic fields, metal detectors, and airport security procedures [13]. They should be informed about the potential risks associated with certain physical activities, such as trampolining, sky diving, sauna use, contact sports, or scuba diving. Ongoing education about device management and long-term safety remains a fundamental element of the nurse's role throughout the patient's life.

Conclusions

Experience and expertise in this specialised field are essential. Clinical nurse specialists and advanced nurse practitioners contribute not only technical proficiency but also a supportive therapeutic environment that addresses both the physical and psychological needs of patients. This holistic approach helps patients feel informed, confident, and well supported as they adapt to life with a DBS device.

This review highlights the unique and evolving role of the DBS clinical nurse specialist and advanced nurse practitioner. The role requires extensive preparation and expertise not only in the clinical specialty itself, but also in education, autonomous practice, advocacy, and research. As members of the neuromodulation team, these nurses make an essential contribution to optimising patient care and improving patient outcomes. The review also underlines the importance of access to dedicated education and regular professional updates for clinical nurse specialists and advanced nurse practitioners working in DBS services.

Implications for Nursing Practice

Deep brain stimulation nurses should play an active role in patient selection, education, perioperative care, device programming, discharge planning, and long-term follow-up. Access to structured training, competency updates, and multidisciplinary collaboration is essential for safe and effective nursing practice in DBS services.

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Corresponding Author:

Sarah Perides

Advanced Nurse Practitioner
Complex Motor Disorders (DBS and ITB)
Evelina London, Guys and St Thomas NHS Trust
Beckett House, 1 Lambeth Palace Road, London, SE1 7EU
Floor 2, Childrens Neurosciences
United Kingdom
e-mail: s.perides@nhs.net

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Author Contributions: Sarah Perides^{A–C, E–G},
Joseph Candelario-Mckeown^{A–C, E–G}

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