



Individualized Care in DBS

A Multidisciplinary Approach

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Disclosures

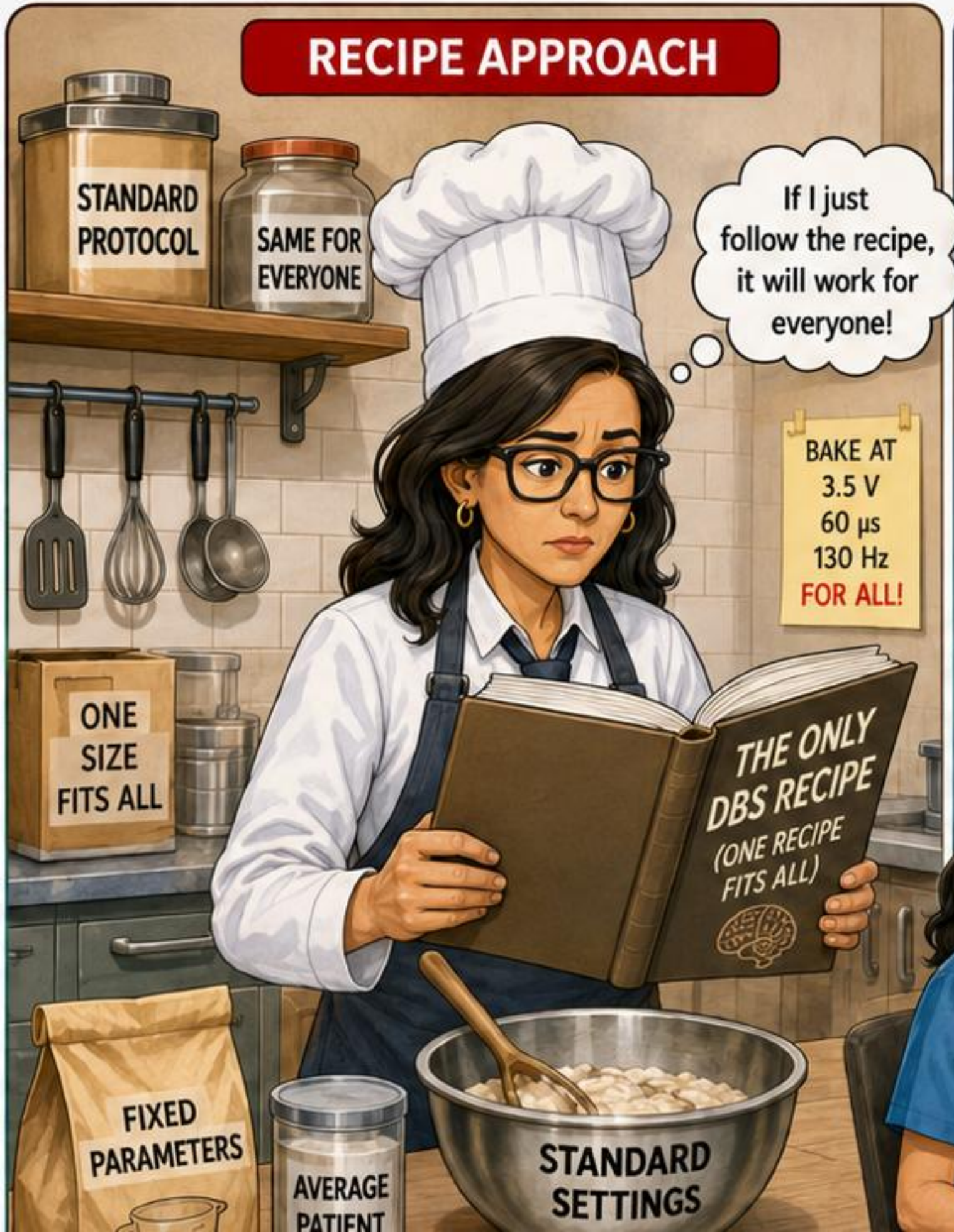
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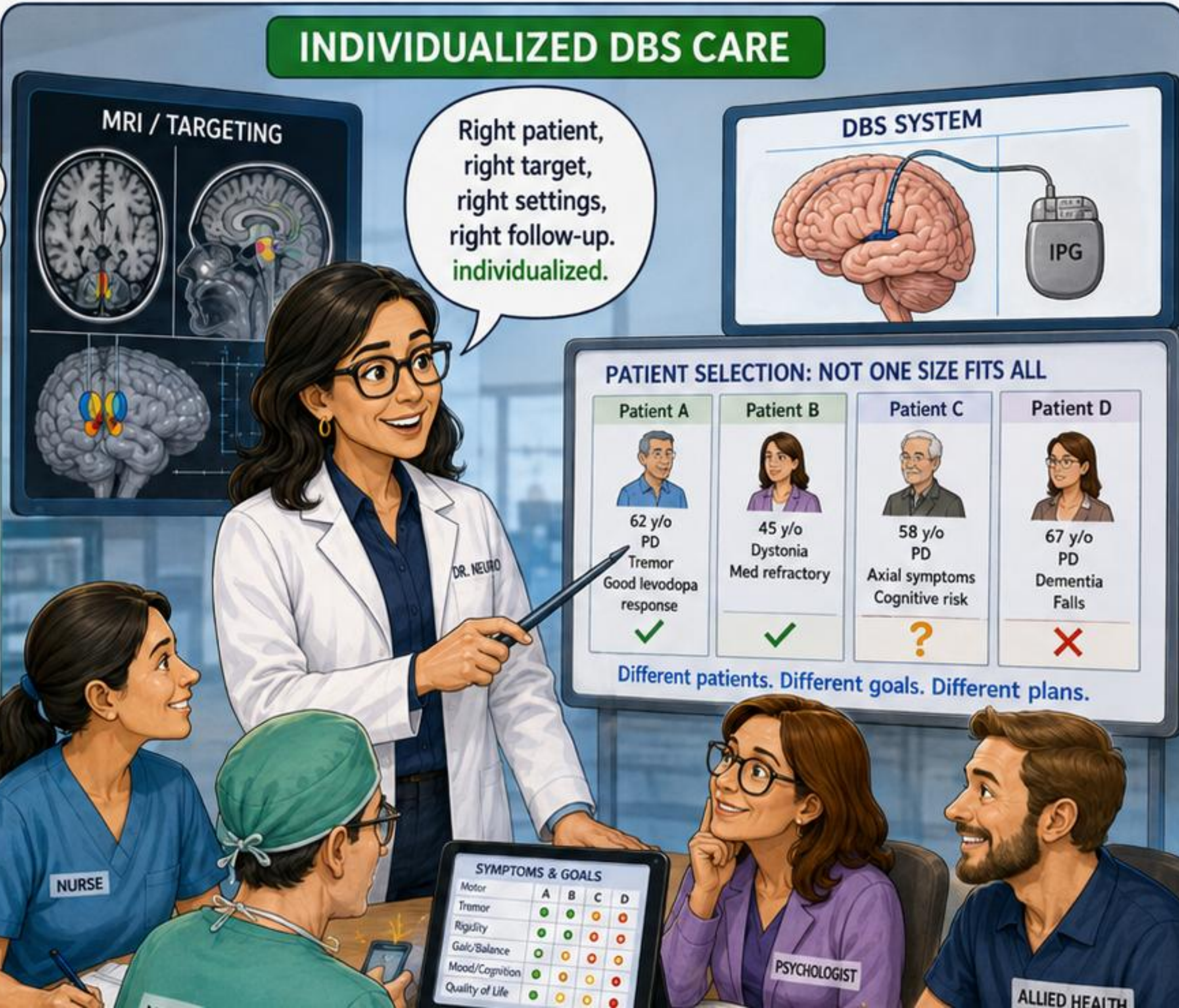
Received honoraria from MDS.

DBS: State of the Art, Not a Cake Recipe

RECIPE APPROACH



INDIVIDUALIZED DBS CARE



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- **DBS is a process, not a procedure** — screening → surgery → programming → years of follow-up.
- **The best motor candidate** can still be a poor overall candidate.
- **If you follow a recipe, you may run into two possible failures** —
 - under-selection → denying the procedure to potential candidates
 - over-selection → in which even a technically perfect surgery yields a disappointed patient.

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The Roadmap



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DBS Neurologist Consultation



1. Review patient history from disease onset to present. This is an important opportunity to identify red flags that would suggest an alternative diagnosis or gaps in management.
2. Review treatments received and responses. Sometimes a side effect to a medication can suggest vulnerability to DBS adverse events. Example: Psychosis caused by amantadine or dopamine agonist.
3. Understand patient symptoms in depth → motor, non-motor, functional impairment.

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DBS Neurologist Consultation



4. Understand patient's expectations and goals. Are the goals realistic?
5. Clearly discuss symptoms that can improve, symptoms that likely will be unchanged, and symptoms that can worsen after DBS.
6. Discuss alternatives to DBS if any.
7. Explain the next steps for candidacy assessments and timelines.

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*Our patients are more complex than the populations represented in
clinical trials and guidelines.*

*The art of DBS neurology is to integrate competing factors and
define the right path for the individual patient.*

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Biological Age

Debunk the hard cutoff while respecting biological age.

- **Chronological age alone is a poor criterion.** The historical ~70 ceiling is convention; evidence supports individualizing.
- **What degrades with age is the substrate:** cognitive reserve, comorbidity, axial/autonomic burden, perioperative risk — assess those.
- **Older patients** get real motor benefit but may show less QoL gain and more cognitive/surgical risk.
- **Use age to raise scrutiny of the other domains, not as a standalone gate.**

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Understand patient symptoms → PD motor fluctuations

Fluctuation	Definition
Predictable wearing-off	Gradual, expected re-emergence of parkinsonian symptoms at the end of an L-dopa dose.
Unpredictable, sudden offs	Acute episodes of akinesia unrelated to the timing of the L-dopa dose.
Dose failure, delayed or partial “on” response	A dose of L-dopa failing to provide the expected benefit in a patient known to be L-dopa responsive; the benefit can be delayed by minutes to hours, or may be absent.
Beginning-of-dose worsening	Worsening of symptoms, especially tremor, in the first few minutes after a dose of L-dopa, before the onset of benefit.
On–off fluctuations / “yo-yoing”	Predictable or unpredictable rapid cycling between being “on” and mobile with dyskinesia, and “off” and immobile — over the course of a dose or over a day.

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Understand patient symptoms → PD dyskinesias

Dyskinesia	Phenomenology
PEAK-DOSE / SQUARE-WAVE	
Chorea / dystonia / ballism	Occurs in the “on” state, 1–2 h after a dose of L-dopa. A mixture of choreic movements of the neck, limbs, trunk and face, with dystonic posturing of the limbs and neck. In more severe cases, ballistic movements can occur.
WEARING-OFF / OFF-PERIOD	
Dystonia	Usually affects the legs and feet (ankle inversion, extension or flexion of the toes). Can be painful and disabling; more frequent in the morning, before the first L-dopa dose. Blepharospasm, jaw opening, and neck/hand posturing can also occur.
Diphasic dyskinesia	Occurs at the beginning- and end-of-dose. Predominantly dystonia affecting the legs, with slow stereotypical alternating movements, sometimes with ballistic kicking. High stepping while walking can produce “funny gaits.”

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Understand patient symptoms → PD axial symptoms

Gait – Balance – Falls

Great appendicular result, persistent falls = Reason for disappointment!

- **Separate** levodopa-responsive axial signs (likely to improve) from refractory freezing / postural instability (won't — may worsen).
 - **Use the L-dopa challenge** to read the axial response specifically

If responsive to
levodopa, e.g.; off
FOG, it may be
improved by STN or
GPi DBS

If resistant to
levodopa, e.g; postural
instability, it may not
improve, or may even
worsen with DBS

If caused by levodopa,
e.g; on FOG, truncal
dystonia, dyskinesia, it
may indirectly improve
after STN DBS.

- **Counsel:** DBS is not a fall-prevention operation.

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Cognition

The single most important modifier of candidacy beyond-motor symptoms.

- Inquire about memory, execute function, language, visuospatial function, activities of daily living, finances, management of medical appointments, medications, driving, etc.
- A screening test can be used in the neurologist visit, but **it absolutely does NOT replace a formal neuropsychological assessment.**
- There is no agreed cognitive cut-score for exclusion; "significant cognitive impairment" is left to care team judgement.
- **Think trajectory, not snapshot:** a patient near the MCI border with a steep decline is more concerning than a patient with the same score, but stable. Sometimes, repeating the cognitive assessment within 6 – 8 months may render useful information.

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Mood & Neuropsychiatric status (PD)

Where silent issues can hide.

- **Screen** for depression, anxiety, apathy before surgery — untreated disease predicts poor satisfaction independent of motor improvement.
- Keep a very low threshold for patients to **meet a psychiatrist**.
- **Have an open discussion about psychiatric risks.** Patients and family want to know and need to know before making a decision.
 - **Apathy** commonly worsens after STN-DBS, often tied to aggressive med reduction
 - **Suicide-risk – absolutely require co-management with a psychiatrist and DBS discussion should be postponed.**

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Impulse control disorders (ICD)

- **Screen everyone:** gambling, hypersexuality, compulsive shopping / eating, punding — driven by dopaminergics, especially agonists.
- **ICD** is not a contraindication for DBS. It may improve with medication. Consider lowering dopamine agonist before surgery. Abrupt agonist withdrawal can cause DAWS.
- Outcome can be heterogeneous — some remit, some persist, a minority of patients experiment new-onset ICD after surgery.
- ICD is a strong reason to coordinate (psychiatry + careful med plan), not to refuse surgery.

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Dopamine dysregulation syndrome (DDS)

Compulsive overuse of dopaminergic medication beyond motor need.

- **Check if patient current medication scheduled is according to the prescribed.**
- Ask about **extra doses taken on demand**. Reasons? How often? Need for prescriptions refill more often than expected.
- Ask collateral information about medication use. Ask for a medication diary.
- **DDS complicates** the post-op med-reduction plan — these patients may resist to lower medication even after STN DBS, developing significant dyskinesias or not tolerating stimulation optimization.
- **Patient** needs psychiatric co-management and sometimes a medication contract.

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Autonomic dysfunction

- **Ask about autonomic dysfunction.**
- Constipation – may be an important drive for dissatisfaction with medication therapy. In some cases, patients may not need DBS if constipation is managed.
- Urinary issues, sexual dysfunction – affect quality of life but typically would not be expected to improve after DBS. Discuss expectations early.
- Orthostatic hypotension – understand timelines and severity, which is important in the differential diagnosis with MSA.
- Affects postoperative safety. It may be a surrogate for disease severity and frailty. Not considered a contraindication but a red flag for peri-operative planning.
- In theory, some patients could improve with medication reduction after STN DBS, but results have been inconsistent.

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Speech & dysphagia (PD, ET, Dystonia)

- **Dysarthria** is a common stimulation-induced effect.
- Discuss patient's goals and expectations. Patient sometimes say: *I'd like to improve my speech* – That's unrealistic!
- Consider professional activity: professors, singers, and people that use their voice for work. Balance risks versus benefit.
- **Pre-existing hypophonia / dysarthria** = higher risk of net worsening. Involve SLP earlier.
- **Dysphagia** can also worsen after DBS, particularly with bilateral stimulation.
- **Dysphagia** is under-assessed and is a real safety issue. Keep a very low threshold to refer for SLP for swallowing assessment and possible modified barium swallowing assessment.
- **In ET**, bilateral VIM carries its own dysarthria risk – relevant to unilateral versus bilateral indication.

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Alternatives

and what has been considered “refractory”

- There is no consensus operational definition of “refractory” in many of the conditions we use DBS for.
- PD tremor – optimized oral therapy – what is being called refractory tremor?
- ET – how many drugs have been tried? Effects and side effects? Doses?
- Cervical dystonia – not responsive to an adequate botulinum toxin? Methods of injections, guidance, different toxins?
- But how many cycles? optimal dose & muscle selection?

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Genetics

- Genetic testing is not needed for all patients with PD undergoing DBS. Request should be driven by family history, age of onset, and phenotype.
- In dystonia, particularly generalized, genetic testing is an expectation.
- *GBA* variants in PD are associated with more rapid cognitive decline, but to date, evidence of DBS altering this trajectory has been inconsistent. Emphasize the importance of the cognitive trajectory preoperatively.
- Other monogenic forms of PD, *LRRK2*, *Parkin*, appear to have a robust response to DBS.
- In dystonia, *DYT1*, *KMT2B* carriers tend to be highly responsive.
- *ATP1A3* carriers tend not to respond meaningfully to DBS.

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*You can only individualize what you assess, and
you can only assess it all as a team.*

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The Neuropsychologist



- **Recommended for all patients undergoing DBS evaluation.**
- Preferably with professionals that have experience with patients with PD and Movement Disorders.
Consider medication timing, fatigue, anxiety, and other factors when scheduling and applying the test.
- Provides the domain-level cognitive profile (not just a screen) that informs candidacy, target choice and post-op comparison.
- **Baseline is essential** so post-op change (e.g. verbal fluency) can be measured, not argued about.
- Also contributes to capacity / expectation assessment.
- Exact battery used might differ between professionals.

Domains assessed & candidate tests

Domain	What is assessed	Test(s)
Premorbid intelligence	Reading / pronouncing phonetically irregular words — estimates maximal past ability; resists decline absent aphasia or severe dementia.	WTAR
Processing speed	Rapid recitation of numbers and days (forwards & backwards); speed on paper visual-scanning / sequencing tasks.	WMS-III Mental Control; D-KEFS Trail Making (control trials)
Language	Naming line drawings of objects; defining words.	Boston Naming Test; WAIS-IV Vocabulary
Visuospatial perception	Matching lines by orientation.	Benton Judgment of Line Orientation
Construction	Copying a detailed complex figure.	Rey Complex Figure (copy)
Attention span & working memory	Temporary holding and real-time manipulation of information; distinct from long-term storage.	WMS-III Spatial Span; WMS-IV Symbol Span; WAIS-IV Digit Span & Letter-Number Sequencing; Brief Test of Attention
Verbal memory	Learning, recall and recognition of a 16-item word list over five encoding trials.	California Verbal Learning Test-II (CVLT-II)
Visual memory	Delayed recall of the previously copied complex figure.	Rey Complex Figure (recall)
Prospective remembering	Remembering to carry out an intended action later without external cues (self-cueing, initiation).	Memory for Intentions Test (MIST)
EXECUTIVE FUNCTIONS		
Clock drawing	Drawing a clock to verbal instruction — planning, organization, self-monitoring.	CLOX 1
Reasoning	Abstract reasoning: verbal similarities between concepts; visual pattern completion.	WAIS-IV Similarities & Matrix Reasoning
Word fluency	Flexible, rapid generation of words meeting examiner-specified criteria.	D-KEFS Verbal Fluency
Resistance to cognitive interference	Naming ink colour while suppressing the automatic word-reading response.	D-KEFS Color-Word Interference Test
Speeded mental flexibility	Rapidly alternating between numbers and letters in sequence.	D-KEFS Trail Making Test
Flexibility in problem solving	Flexible problem solving without a specified approach; error analysis for perseveration & set-maintenance failures.	Wisconsin Card Sorting Test (WCST)

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The Psychiatrist



- Given the burden of mood symptoms in PD, all patients ideally should be seen by a neuropsychiatrist or a psychiatrist with interest in movement disorders.
- Mood issues are also very prevalent in dystonia, and patients might benefit from seeing a psychiatrist.
- **Assesses and treat depression, anxiety, apathy, psychosis, ICD / DDS before surgery – and co-manages after.**
- Critical to the suicide-risk conversation and the post-op medication-reduction plan (apathy, DAWS, DDS).
- Identify psychiatric risks beyond the patient history – strong family history of bipolar disorder, suicide, etc.
- When possible, they should attend the DBS conferences to discuss sensitive issues identified during their assessments and management plan.

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DBS nurse & advanced practice providers



Frequently the anchor patients actually rely on.

- In many places, run much of pre-op assessment (levodopa challenge, rating scales, videotaping) and pre-op education.
- In the post-op, perform device programming and follow-up (common in most North American centers); less common in Latin America.
- Detect (and sometimes manage) problems between physician visits: mood changes, ICD, hardware issues.
- Often the patient's main contact – continuity of care. **Often the difference between a supported patient and a lost one.**

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REVIEW



Levodopa challenge test: indications, protocol, and guide

Gerard Saranza¹ · Anthony E. Lang^{1,2,3}

Table 1 Indications and doses used in an acute levodopa challenge test

Purpose of LCT	Dose of levodopa used
Screening prior to invasive treatment, e.g., DBS or LCIG	120% of morning levodopa dose Note: if repeated, higher doses at 150% and 200% of the morning dose may be used, especially in patients with drug-resistant tremor
Re-evaluation of motor response	Same as or 120% of morning levodopa dose
Diagnosis of PD among de novo patients and differentiation from other forms of parkinsonism	Most studies have used 250/25 mg of levodopa/decarboxylase inhibitor while one study used escalating doses at 100, 150, 200, 300 mg of levodopa on four consecutive days ^a
Characterization of dyskinesias	Same as maintenance dose at the time LCT is done
Clinical or experimental trials	Any dose, up to supratherapeutic dose at 150% of the morning maintenance dose

Table 2 Sample of an acute levodopa challenge test (LCT) sheet

GENERAL INFORMATION										
Name					Date					
Current PD Medications:					Time of last levodopa intake					
					Breakfast taken					
					Morning levodopa equivalent dose					
					Dose of levodopa to be given					
Consent for LCT	☐ Yes ☐ No				Consent for videotape	☐ Yes ☐ No				
PERIODS OF ASSESSMENT										
	Legend: Period A = off state Period B = onset of effect Period C= peak of benefit Period D= wearing off state Period E= end of dosing cycle									
	ASSESSMENT									
	Period	A		B		C		D		E
	Time									
	Blood pressure									
Scores	Raw Score	Raw Score	% Change	Raw Score	% Change	Raw Score	%Change	Raw Score		
UPDRS III Total Score										
Bradykinesia Sub-score										
Rigidity Sub-score										
Tremor Sub-score										
12 m walk time (sec)										
Subjective % Improvement										
Subjective Reports										
Dyskinesias Observed										
LEVODOPA RESPONSIVENESS										
$\% LR = \frac{OFF\ UPDRS\ III\ Total\ Score - Peak\ ON\ UPDRS\ III\ Total\ Score}{OFF\ UPDRS\ III\ Score} \times 100 = \underline{\hspace{2cm}}$										
Symptoms which improved										
Pattern of dyskinesia noted										
Plan										
Performed by:										

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Physiotherapist (PT) / Occupational Therapist (OT)



- Characterizes axial function, gait, balance and falls risk — the L-dopa resistant features DBS won't fix.
- Sets expectations pre-op and may contribute to post-op rehab
- Helps in the recognition of disease vs stimulation-induced axial side effects in the troubleshooting phase.
- Part of turning a good motor result into a good functional outcome.

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Physiotherapist (PT) and Occupational Therapist (OT)



Guidetti et al.
Journal of NeuroEngineering and Rehabilitation (2025) 22:80
<https://doi.org/10.1186/s12984-025-01616-w>

Journal of NeuroEngineering
and Rehabilitation

RESEARCH

Open Access



Is physical therapy recommended for people with parkinson's disease treated with subthalamic deep brain stimulation? a delphi consensus study

Matteo Guidetti¹, Sara Marceglia^{1*}, Tommaso Bocci^{1,2}, Ryan Duncan^{3,4}, Alfonso Fasano^{5,6,7,8}, Kelly D. Foote^{9,10}, Clement Hamani^{11,12,13}, Joachim K. Krauss¹⁴, Andrea A. Kühn^{14,15,16,17,18,19}, Francesco Lena^{20,21}, Patricia Limousin²², Andres M. Lozano^{5,6,23}, Natale V. Maiorana¹, Nicola Modugno²¹, Elena Moro²⁴, Michael S. Okun^{25,26}, Serena Oliveri^{1,2}, Marco Santilli²¹, Alfons Schnitzler^{27,28}, Yasin Temel²⁹, Lars Timmermann³⁰, Veerle Visser-Vandewalle³¹, Jens Volkmann³² and Alberto Priori^{1,2}

Methods After summarizing the few available findings through a systematic scoping review, we identified clinically and academically experienced DBS clinicians (n=21) to discuss the challenges related to PT following STN-DBS. A 5-point Likert scale questionnaire was used and based on the results of the systematic review, thirty-nine questions were designed and submitted to the panel—half related to general considerations on PT following STN-DBS, and half related to PT treatments.

Results Despite the low-to-moderate quality of data, the few available rehabilitation studies suggested that PT could improve dynamic and static balance, gait performance and posture in the population with PD receiving STN-DBS. Similarly, the panellists strongly agreed that PT might help improve motor symptoms and quality of life, and it may be prescribed to maximize the effects of stimulation. The experts agreed that physical therapists could be part of the multidisciplinary team taking care of the patients. Also, they agreed that conventional PT, but not massage or manual therapy, should be prescribed because of the specificity of STN-DBS implantation.

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The Speech-language pathologist (SLP)



- Baseline & follow-up speech (dysarthria / hypophonia) and swallow (aspiration risk) assessment.
- Delivers therapy and informs programming when stimulation worsens speech.
- Useful to consider also before proceeding with second side implant or HIFU.
- Particularly relevant in patients with pre-existing hypophonia and bilateral stimulation.

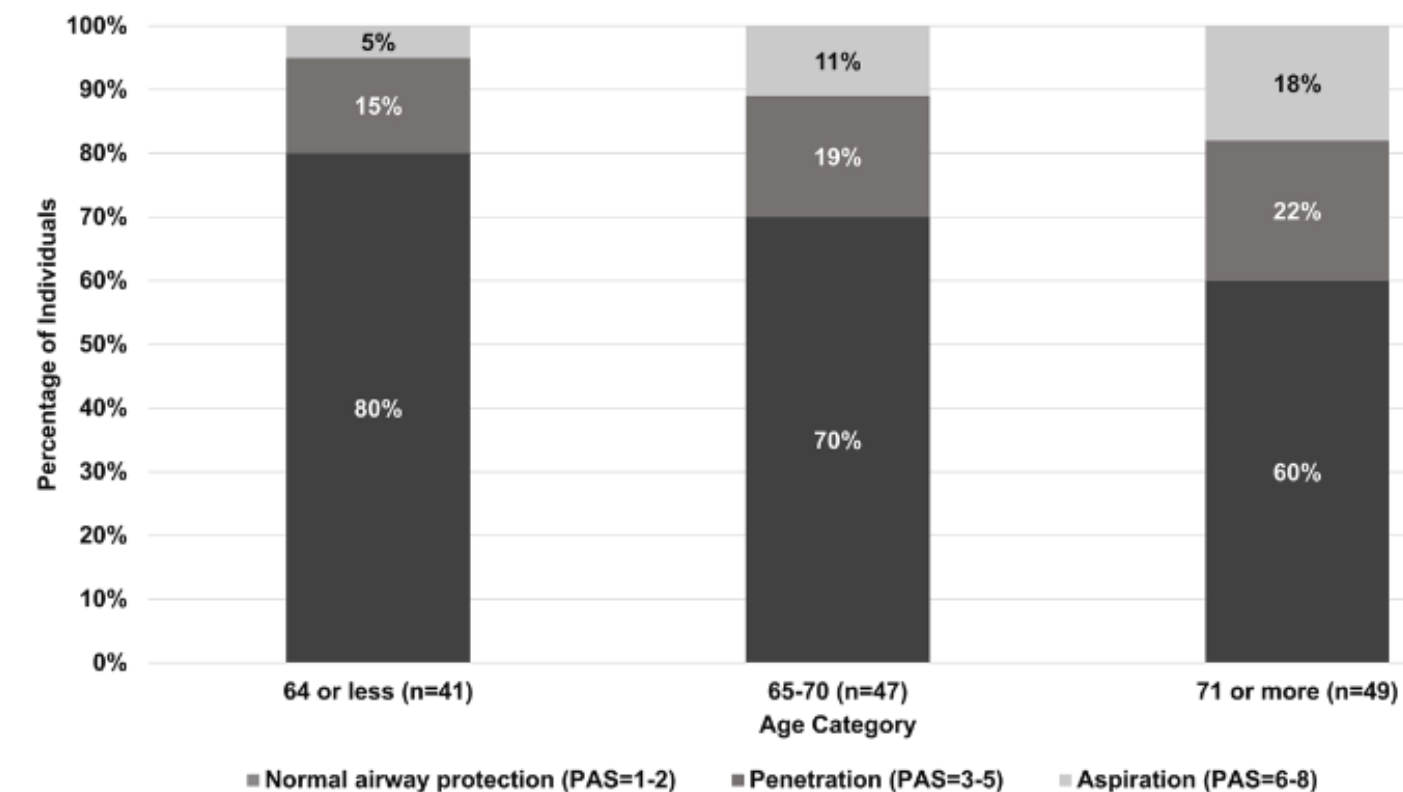


Fig. 1. Penetration-Aspiration Scale (PAS) scores by age category.

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The Speech-language pathologist (SLP)



REVIEW

Speech and Deep Brain Stimulation in Parkinson's Disease, Essential Tremor, and Dystonia: A Systematic Review and Meta-analysis

Elina Tripoliti, PhD,^{1,2*} Takashi Tsuboi, MD, PhD,^{3*} Michael T. Barbe, MD, PhD,⁴ Mario Sousa, MD,^{5,6} Julie Barkmeier-Kraemer, PhD,^{7,8} Hannah Jergas, MD, PhD,⁴ Gaia Arno, BSc,⁹ Nicole Buie, BSc,⁹ Mikayla Day, BSc,⁹ Petr Krýže, MSc,¹⁰ Jayson R. Nelson, BSc,¹¹ Aaron E.L. Warren, PhD,¹² Shervin Rahimpour, MD,¹¹ Jan Ruzs, PhD,¹⁰ Paul Krack, MD, PhD,⁵ and Kristina Simonyan, MD, PhD, DrMed^{9,13}

ABSTRACT: Deep brain stimulation (DBS) effectively treats motor symptoms in movement disorders but often compromises speech through incompletely defined mechanisms. We conducted a PROSPERO-registered systematic review and meta-analysis of publications through August 2024 (CRD42024527738). Among 2726 screened records, we included 184 studies: 131 in Parkinson's disease (PD), 32 in essential tremor (ET), and 21 in dystonia, assessing perceptual, acoustic, and patient-reported speech outcomes. Meta-analyses showed that **subthalamic nucleus DBS in PD resulted in poorer speech intelligibility compared with best medical treatment (effect size -0.24 ; 95% confidence interval: -0.46 to -0.03 ; $P = 0.027$), with state-dependent decline under active stimulation on longitudinal analysis (Unified Parkinson's Disease Rating Scale Part III item 18 monthly change: medication on $+0.016$, $P < 0.001$; medication off $+0.002$, $P = 0.50$). In ET, DBS consistently suppressed vocal tremor but**

increased the risk of dysarthria, particularly with bilateral stimulation. Dystonia outcomes showed greater heterogeneity. Across disorders, sustained phonation measures improved, whereas connected speech performance worsened, indicating selective vulnerability of complex motor tasks. Neuroanatomical mapping identified two nonexclusive mechanisms: current spread to corticobulbar fibers producing spastic speech features and to the cerebellothalamocortical pathway producing ataxic features. Hypokinetic and stuttering-like phenotypes also occurred but likely reflect network-level interactions rather than tract-specific spread. These tract-mediated and network-level alterations appear to interact with hemispheric lateralization, medication state, and longer-term plasticity to produce complex clinical phenotypes. We outline a clinical framework integrating systematic screening, phenotype identification, and targeted programming adjustments. Enhanced speech assessment, precise field mapping, and adaptive DBS

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Social worker (or counsellor)



- **Assessment:** biopsychosocial evaluation, background, baseline health and functioning
- **Support & environment:** social supports, living conditions, basic needs, transport
- **Risk screening:** substance use, abuse, safety and suicide risk
- **Planning:** insurance, advance directives, post-op care plan (+ backup), resources
- **Counseling & liaison:** goals, coping, anxiety, brief counseling/referral, team communication

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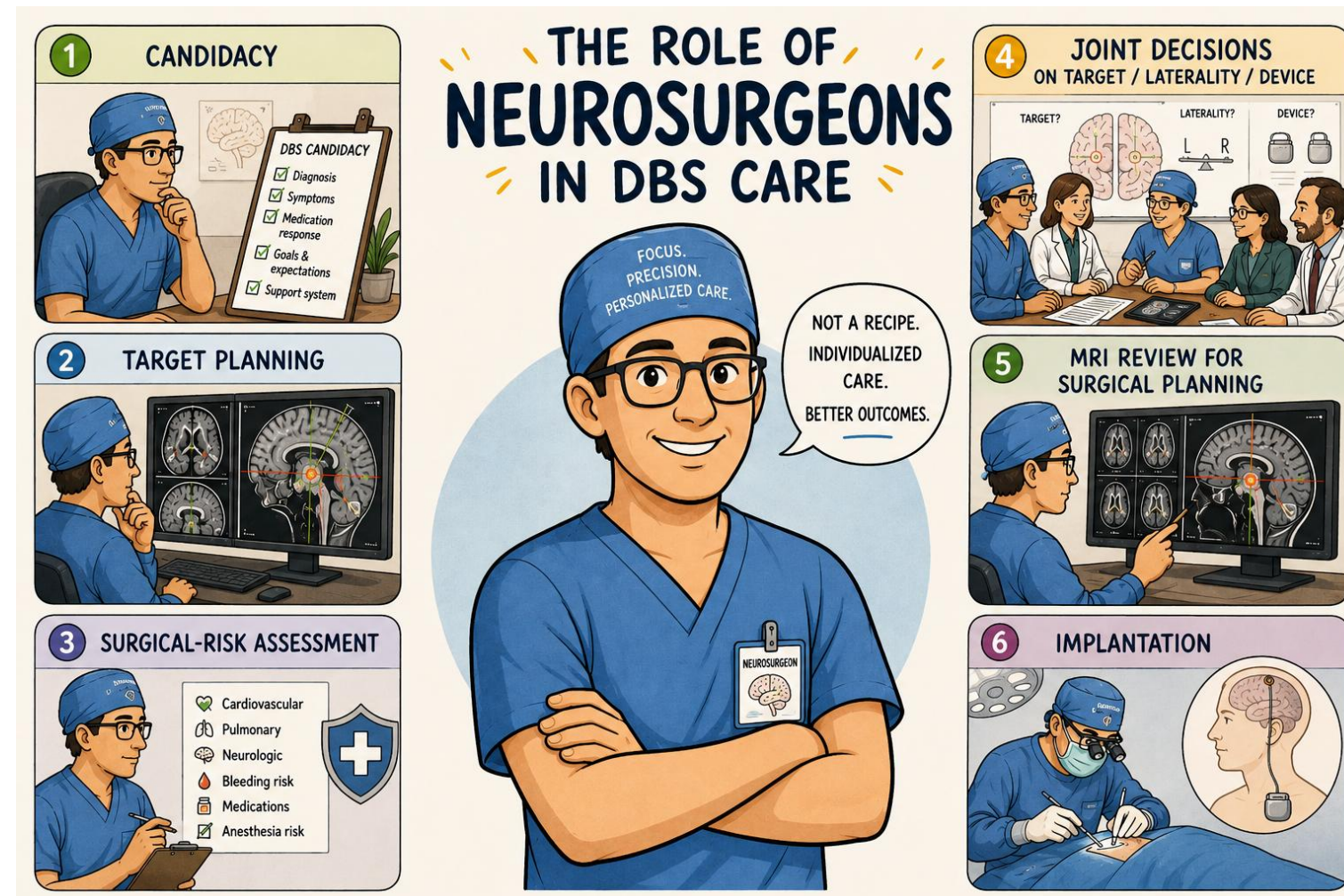


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The Functional Neurosurgeon



- Candidacy
- Target planning
- Surgical-risk assessment and discussion
- Joint decisions on target / laterality / device
- MRI review for surgical planning
- Implantation



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Patients with and without a care partner

- A care partner supports post-op logistics, med changes, device handling, early detection of mood / behavioral change.
- Absence is not an exclusion, but it raises the required intensity of the formal team (nursing, social work) to support that individual.
- Assess the partner too: burden, expectations, their own capacity: an overwhelmed partner is a risk, not a guarantee.
- Manage partner's expectations as well!
- The DBS team may need to scale up.

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Summary: An individualized candidacy framework

- 1 • **Diagnosis & indication:** right disease, right phenotype, alternatives explored.
- 2 • **Prediction of Outcomes:** Phenotype, L-dopa response (PD), tremor characteristics and localization (ET), dystonia phenotype distribution, genetics (dystonia).
- 3 • **Modifiers:** cognition, mood / behavior (ICD/DDS), speech/swallow, autonomic, age, genetics – **may shift target, timing or expectations.**
- 4 • **Support & expectations:** care partner, social access, education, and a documented expectation conversation.
- 5 • **Team decision:** multidisciplinary review by a specialist to relevant concerns.

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The DREAM team	The minimum you must have
DBS neurologist + functional neurosurgeon	MD neurologist + functional neurosurgeon (non-negotiable)
Dedicated DBS nurse / NP / APP	A named coordinator (nurse / APP) for continuity & triage
Neuropsychologist — full battery, pre + post	Access to formal neuropsychological assessment
Neuropsychiatrist embedded in the team	A psychiatry pathway that can assess & stabilize
PT, SLP, social worker, on the team	Reliable referral routes to PT, SLP & social work
Regular multidisciplinary candidacy conference	Structured case review before every offer of surgery
Structured education + patient outcome tracking	Documented pre-op and post-op education



**Being eligible doesn't mean being satisfied.
Individualization is essential to determine who will actually benefit from DBS.**