A Submission to the MBS Continuous Review: Modernising MBS Tilt Table Testing for Diagnosis of Postural Orthostatic Tachycardia Syndrome (POTS)

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1. Review Topic

Title:
Modernising MBS Tilt Table Testing for Diagnosis of Postural Orthostatic Tachycardia Syndrome (POTS)

Background and Summary:
There has been an exponential increase in diagnoses of Postural Orthostatic Tachycardia Syndrome (POTS), particularly following the COVID-19 pandemic. International studies indicate that up to 80% of individuals with Long COVID may exhibit autonomic dysfunction, with POTS emerging as the most common phenotype. Despite this, Australia currently lacks an MBS item that aligns with the internationally recommended diagnostic standard for POTS.

The only MBS item available for tilt table testing (TTT) is 11704, designed primarily for evaluating syncope which is not a predominant feature of POTS. This item includes requirements—such as intravenous access, continuous specialist attendance, and resuscitation equipment—that reflect a model of pharmacologic provocation TTT, rather than passive TTT which is recommended in current international guidelines for POTS.

The European Federation of Autonomic Societies (EFAS) recommends non-provocation tilt table testing or active stand testing for investigation of a POTS diagnosis. There is an urgent need to revise the MBS to support safe, accessible, and evidence-based diagnostic services for this growing population.

2. What is the problem with the current approach/model of care for patients?

MBS Item 11704 does not reflect best-practice diagnostic standards for Postural Orthostatic Tachycardia Syndrome (POTS) and inadvertently creates structural barriers to diagnosis and care. The item was designed for evaluating syncope and includes requirements such as intravenous cannulation, access to defibrillation and ventilation, and continuous specialist attendance. These features imply the use of pharmacologic provocation, which is *not* recommended for POTS diagnosis and contradicts current international guidelines.

This outdated model prevents access to testing in community or outpatient settings where the majority of POTS patients could be appropriately and safely assessed using non-provoked tilt testing or active stand test protocols. As a result, POTS assessments are limited to a small number of tertiary centres, if offered at all, and often only on a self-funded basis.

This creates multiple problems across the healthcare system:

- **Prolonged diagnostic delay:** Patients with POTS experience an average diagnostic delay of 7 years, with more than one-quarter waiting over a decade. This delay contributes to avoidable disability, missed treatment opportunities, and psychological harm.
- **Inequity of care:** Patients in regional, rural, and lower-income settings are disproportionately affected, as they are less able to travel to tertiary centres or pay privately for diagnosis.
- **Cost inefficiency:** Delayed diagnosis leads to repeated emergency department visits, unnecessary referrals, extensive investigations, and avoidable interactions with the health care system—often without resolution. These indirect costs far exceed the cost of accessible diagnostic testing.
- **Increased burden on consultant services:** The current model requires specialist-level time and infrastructure for what is, in most cases, a low-risk outpatient procedure. This results in a drain on consultant availability, diverting them from more complex clinical care and reducing system efficiency.

In short, the current item fails to support coordinated, accessible, and sustainable care for a condition with rising prevalence and clear diagnostic protocols.

3. What is the extent of the problem?

Postural Orthostatic Tachycardia Syndrome (POTS) is a debilitating, chronic form of autonomic dysfunction most commonly affecting young women of childbearing age. While long under-recognised, it has become increasingly prevalent in the wake of the COVID-19 pandemic. Emerging international data, including analyses of ICD-10 coding, estimate that 3.4% of people infected with SARS-CoV-2 go on to develop POTS, particularly in vulnerable cohorts such as women aged 15–45.[1,2]

Conservatively, this suggests that over 500,000 Australians may be affected by POTS. Yet despite its increasing burden, POTS remains underdiagnosed and poorly understood by many clinicians. Access to formal diagnostic testing is limited, inequitable, and inappropriately constrained by the current Medicare item structure.

Published findings from the Australian POTS Patient Registry (2021–2024) illustrate the extent of the diagnostic gap and the broader system-wide impacts:[3]

- Mean diagnostic delay of 7.0 years for women (3.8 years for men), with over 25% waiting more than a decade
- More than half of participants had presented to an emergency department for symptoms, with a mean of 5.2 visits prior to diagnosis
- Patients had seen an average of 5.2 doctors before receiving a formal diagnosis
- Quality of life was severely impaired, with a mean EQ-5D-5L utility score of 0.591 (on a scale where 1.0 = full health)

These delays and misdiagnoses contribute to a cycle of escalating healthcare utilisation, with POTS patients often navigating between cardiology, neurology, rheumatology, and psychiatry before receiving appropriate care. This inefficiency impacts both public and private systems.

Without intervention, the combination of increasing prevalence, inadequate diagnostic access, and lack of national guidance will exacerbate:

- Pressure on emergency and acute care services
- Systemic inequities, particularly in regional and rural communities
- Lost productivity and early withdrawal from education or employment, particularly among young women

In summary, the current diagnostic environment fails to meet the needs of a large and growing patient population. Reforming the MBS to support appropriate, early diagnosis is essential to improve outcomes and reduce long-term costs.

4. MBS Relevance

This issue is best addressed through reform of the Medicare Benefits Schedule (MBS) because the core barrier to diagnosis lies within the structure and conditions of the existing MBS item (Item 11704). This item was originally designed for evaluating syncope and includes requirements such as intravenous cannulation, access to resuscitation equipment, and continuous specialist attendance. These features imply the use of pharmacologic provocation, which is **not recommended for POTS** in international guidelines[4] and is inconsistent with modern clinical practice.

Specifically, MBS Item 11704:

- Imposes clinical infrastructure requirements such as intravenous cannulation, access to defibrillation and ventilation, and continuous specialist attendance
- Implies a model of pharmacological provocation, which is not recommended for POTS according to the European Federation of Autonomic Societies [4]
- Restricts delivery of appropriate testing to a small number of hospital-based or tertiary centres, excluding outpatient and community-based care
- Limits GP-led coordination, as referring doctors have no Medicare-recognised pathway to initiate non-provoked autonomic testing

This outdated design results in:

- Diagnostic delay, especially for patients in rural and outer metropolitan regions
- Reduced care options for GPs and specialists seeking to deliver coordinated, evidence-based assessments
- Increased health system burden, including inappropriate ED presentations and prolonged specialist involvement

The MBS is the most appropriate mechanism to resolve this issue, for the following reasons:

- It defines which diagnostic services are accessible to patients under public funding
- It shapes the service delivery model, including who can provide care and in what settings
- It ensures alignment of Medicare-funded services with evolving clinical evidence, population need, and sustainability priorities
- It can be amended to explicitly support modern testing methods, such as non-provoked tilt table and active stand tests

While the Australian POTS Foundation (APF) and clinical collaborators have undertaken extensive system-strengthening work—including:

- The successful nomination and implementation of an ICD-10-AM code for POTS (G90.8), which has been accepted and will be adopted nationally from 1 July 2025 to standardise recognition across clinical, administrative, and research systems
- Active engagement with the Therapeutic Goods Administration (TGA) to progress repurposing of midodrine for the treatment of POTS, addressing a major treatment gap
- Development of evidence-based diagnostic pathways and training tools for clinicians
- Delivery of nationally accredited education for General Practice, including a RACGP CPD-accredited training module, currently funded by APF
- Dissemination of clinical and patient decision-support tools across cardiology, neurology, allied health, and primary care settings

... none of these initiatives can overcome the structural limitations imposed by the current MBS funding model.

No alternative public mechanism (e.g. state-based funding, research grants, or hospital funding agreements) is available to support the delivery of non-provoked autonomic testing under Medicare. Without an appropriate MBS item:

- Evidence-based testing remains unavailable to most Australians
- Primary care cannot coordinate appropriate assessment and care

- Efforts to build clinical capability and patient pathways are constrained at the point of diagnostic access

Updating the MBS is therefore essential to:

- Translate national investments and clinician training into real-world benefit
- Enable timely, accurate diagnosis
- Reduce downstream healthcare costs and inefficiencies
- Support a sustainable, high-value system of care for a growing cohort of predominantly young Australians affected by POTS

5. Outcome

Proposed Outcome:
We propose the creation of a new MBS item, or the amendment of existing MBS Item 11704, to support appropriate diagnostic testing for Postural Orthostatic Tachycardia Syndrome (POTS), in alignment with current international clinical guidelines.

The revised item would:

- Fund non-provocation tilt table testing or active stand testing for autonomic dysfunction, consistent with European Federation of Autonomic Societies (EFAS) recommendations[4]
- Remove outdated clinical infrastructure requirements, such as IV cannulation, pharmacologic provocation, continuous specialist presence, and resuscitation equipment
- Allow testing to be delivered in outpatient or community settings (e.g. primary care practices, autonomic clinics, cardiology practices, allied health-led services)
- After ordering of the tilt table or active stand test from a requesting practitioner, permit testing to be conducted by appropriately trained allied health professionals or technicians, with a minimum of two people on site trained in cardiopulmonary resuscitation.

This approach reflects the best-practice, low-risk nature of these assessments when used for POTS, and ensures Australian practice is consistent with global standards.

Benefits:

- **Reduced Time to Diagnosis & Earlier Intervention:** Enables more timely identification of POTS, reducing years of diagnostic delay, unnecessary referrals, and healthcare avoidance, while improving quality of life through earlier symptom management
- **Improved Equity of Access:** Expands availability of testing to those outside metropolitan centres and private specialist clinics, including rural and regional Australians
- **Cost-Effectiveness:** Avoids unnecessary emergency department visits and repeated investigations by supporting accurate diagnosis earlier in the care journey
- **Sustainability:** Enables testing in outpatient and community settings, reducing dependence on hospital-based services and freeing up specialist time for complex cases

Potential Risks and Mitigation:

- **Risk:** Inappropriate use or over-claiming

    - *Mitigation:* Clear item descriptors with specific clinical indications and referral expectations
- **Risk:** Variability in delivery or provider training
    - *Mitigation:* National guidance on protocols, and requirement for supervision by a qualified medical practitioner
- **Risk:** Fragmentation of care
    - *Mitigation:* Encourage integration into GP-led coordinated care pathways, with results shared across electronic health records

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