



**Australian Government**  
**Repatriation Medical Authority**

**Statement of Principles**  
**concerning**  
**NARCOLEPSY**  
**(Balance of Probabilities)**  
**(No. 12 of 2022)**

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The Repatriation Medical Authority determines the following Statement of Principles under subsection 196B(3) of the *Veterans' Entitlements Act 1986*.

Dated 24 December 2021

The Common Seal of the  
Repatriation Medical Authority  
was affixed to this instrument  
at the direction of:

Professor Terence Campbell AM  
Chairperson

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**1 Name**

This is the Statement of Principles concerning *narcolepsy (Balance of Probabilities)* (No. 12 of 2022).

**2 Commencement**

This instrument commences on 31 January 2022.

**3 Authority**

This instrument is made under subsection 196B(3) of the *Veterans' Entitlements Act 1986*.

**4 Repeal**

The Statement of Principles concerning narcolepsy No. 8 of 2014 (Federal Register of Legislation No. F2014L00025) made under subsections 196B(3) and (8) of the VEA is repealed.

**5 Application**

This instrument applies to a claim to which section 120B of the VEA or section 339 of the *Military Rehabilitation and Compensation Act 2004* applies.

**6 Definitions**

The terms defined in the Schedule 1 - Dictionary have the meaning given when used in this instrument.

**7 Kind of injury, disease or death to which this Statement of Principles relates**

- (1) This Statement of Principles is about narcolepsy and death from narcolepsy.

*Meaning of narcolepsy*

- (2) For the purposes of this Statement of Principles, narcolepsy:
- (a) means a chronic neurological disorder of sleep regulation and wakefulness characterised by disabling, excessive and irresistible daytime sleepiness lasting for at least 3 months, with varying amounts of cataplexy, hypnagogic hallucinations, and sleep paralysis; and
  - (b) includes:
    - (i) narcolepsy with cataplexy (narcolepsy type 1); and
    - (ii) narcolepsy without cataplexy (narcolepsy type 2); and

- (c) excludes:
- (iii) early onset narcolepsy; and
  - (iv) daytime sleepiness caused by another condition which disrupts the duration or quality of sleep.

Note 1: Narcolepsy type 1 is characterised by cataplexy along with sleepiness at the onset of the disorder. It is related to a deficiency of orexin due to selective loss of orexin-secreting neurons in the hypothalamus, with little or no detectable orexin in the cerebrospinal fluid.

Note 2: Narcolepsy type 2 is characterised by sleepiness that may occur with hypnagogic hallucinations and sleep paralysis, but cataplexy is not present. Levels of cerebrospinal fluid orexin are usually normal.

Note 3: The diagnosis of narcolepsy is established by appropriate clinical testing, including sleep studies, the multiple sleep latency test (MSLT) and measurement of orexin levels in the cerebrospinal fluid.

Note 4: Examples of other conditions that can cause daytime sleepiness include circadian rhythm sleep-wake disorders (for example, rotating shift work), insufficient sleep, and the effect of medication or substances or their withdrawal.

Note 5: *cataplexy*, *hypnagogic hallucinations* and *sleep paralysis* are defined in the Schedule 1 - Dictionary.

- (3) While narcolepsy attracts ICD-10-AM code G47.4, in applying this Statement of Principles the meaning of narcolepsy is that given in subsection (2).
- (4) For subsection (3), a reference to an ICD-10-AM code is a reference to the code assigned to a particular kind of injury or disease in *The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM)*, Tenth Edition, effective date of 1 July 2017, copyrighted by the Independent Hospital Pricing Authority, ISBN 978-1-76007-296-4.

#### *Death from narcolepsy*

- (5) For the purposes of this Statement of Principles, narcolepsy, in relation to a person, includes death from a terminal event or condition that was contributed to by the person's narcolepsy.

Note: *terminal event* is defined in the Schedule 1 - Dictionary.

## **8 Basis for determining the factors**

On the sound medical-scientific evidence available, the Repatriation Medical Authority is of the view that it is more probable than not that narcolepsy and death from narcolepsy can be related to relevant service rendered by veterans or members of the Forces under the VEA, or members under the MRCA.

Note: *MRCA*, *relevant service* and *VEA* are defined in the Schedule 1 - Dictionary.

## 9 Factors that must exist

At least one of the following factors must exist before it can be said that, on the balance of probabilities, narcolepsy or death from narcolepsy is connected with the circumstances of a person's relevant service:

- (1) having concussion or moderate to severe traumatic brain injury within the 2 years before the clinical onset of narcolepsy, and in the case of sustained unconsciousness following injury to the head, the clinical onset of narcolepsy occurred within 2 years of regaining consciousness;
- (2) having a neurosurgical procedure involving the hypothalamus, midbrain or brainstem, within the 2 years before the clinical onset of narcolepsy;
- (3) undergoing a course of therapeutic radiation for cancer, where the brain was in the field of radiation, within the 3 years before the clinical onset of narcolepsy;
- (4) having a neurological disease, neurodegenerative disease or a paraneoplastic neurological syndrome, where the disease or syndrome involves the hypothalamus, midbrain or brainstem, within the 2 years before the clinical onset of narcolepsy;

Note: Examples of neurological diseases, neurodegenerative diseases or paraneoplastic neurological syndromes that can involve the hypothalamus, midbrain or brainstem include:

- (i) cerebrovascular accident;
- (ii) disseminated encephalomyelitis;
- (iii) hypoxic cerebral insult;
- (iv) multiple sclerosis;
- (v) neuromyelitis optica spectrum disorder; and
- (vi) Parkinson's disease.

- (5) having:
  - (a) a benign or malignant neoplasm; or
  - (b) a non-malignant space occupying lesion;involving the hypothalamus, midbrain or brainstem within the 2 years before the clinical onset of narcolepsy;

Note 1: Examples of neoplasms that can involve the hypothalamus, midbrain or brainstem include lymphoma, glioma and craniopharyngioma.

Note 2: Examples of non-malignant space occupying lesions that can involve the hypothalamus, midbrain or brainstem include neurosarcoidosis and vascular malformations.

- (6) receiving the adjuvanted influenza H1N1 vaccine Pandemrix<sup>TM</sup> within the 2 years before the clinical onset of narcolepsy;

- (7) having infection of the pharynx with *Streptococcus pyogenes* within the 3 years before the clinical onset of narcolepsy;
- (8) having concussion or moderate to severe traumatic brain injury within the 2 years before the clinical worsening of narcolepsy, and in the case of sustained unconsciousness following injury to the head, the clinical worsening of narcolepsy occurred within 2 years of regaining consciousness;
- (9) having a neurosurgical procedure involving the hypothalamus, midbrain or brainstem, within the 2 years before the clinical worsening of narcolepsy;
- (10) undergoing a course of therapeutic radiation for cancer, where the brain was in the field of radiation, within the 3 years before the clinical worsening of narcolepsy;
- (11) having a neurological disease, neurodegenerative disease or a paraneoplastic neurological syndrome, where the disease or syndrome involves the hypothalamus, midbrain or brainstem, within the 2 years before the clinical worsening of narcolepsy;

Note: Examples of neurological diseases, neurodegenerative diseases or paraneoplastic neurological syndromes that can involve the hypothalamus, midbrain or brainstem include:

- (i) cerebrovascular accident;
- (ii) disseminated encephalomyelitis;
- (iii) hypoxic cerebral insult;
- (iv) multiple sclerosis;
- (v) neuromyelitis optica spectrum disorder; and
- (vi) Parkinson's disease.

- (12) having:
  - (a) a benign or malignant neoplasm; or
  - (b) a non-malignant space occupying lesion;
 involving the hypothalamus, midbrain or brainstem within the 2 years before the clinical worsening of narcolepsy;

Note 1: Examples of neoplasms that can involve the hypothalamus, midbrain or brainstem include lymphoma, glioma and craniopharyngioma.

Note 2: Examples of non-malignant space occupying lesions that can involve the hypothalamus, midbrain or brainstem include neurosarcoidosis and vascular malformations.

- (13) receiving the adjuvanted influenza H1N1 vaccine Pandemrix™ within the 2 years before the clinical worsening of narcolepsy;
- (14) having infection of the pharynx with *Streptococcus pyogenes* within the 3 years before the clinical worsening of narcolepsy;
- (15) inability to obtain appropriate clinical management for narcolepsy.

## **10 Relationship to service**

- (1) The existence in a person of any factor referred to in section 9, must be related to the relevant service rendered by the person.
- (2) The factors set out in subsections 9(8) to 9(15) apply only to material contribution to, or aggravation of, narcolepsy where the person's narcolepsy was suffered or contracted before or during (but did not arise out of) the person's relevant service.

## **11 Factors referring to an injury or disease covered by another Statement of Principles**

In this Statement of Principles:

- (1) if a factor referred to in section 9 applies in relation to a person; and
- (2) that factor refers to an injury or disease in respect of which a Statement of Principles has been determined under subsection 196B(3) of the VEA;

then the factors in that Statement of Principles apply in accordance with the terms of that Statement of Principles as in force from time to time.

# Schedule 1 - Dictionary

Note: See Section 6

## 1 Definitions

In this instrument:

**cataplexy** means a transient attack of extreme generalised weakness, often precipitated by an emotional response, such as surprise, fear or anger.

**hypnagogic hallucinations** means vivid, often frightening visual, tactile or auditory hallucinations that occur as the person is falling asleep.

**MRCA** means the *Military Rehabilitation and Compensation Act 2004*.

**narcolepsy**—see subsection 7(2).

**relevant service** means:

- (a) eligible war service (other than operational service) under the VEA;
- (b) defence service (other than hazardous service and British nuclear test defence service) under the VEA; or
- (c) peacetime service under the MRCA.

Note: **MRCA** and **VEA** are also defined in the Schedule 1 - Dictionary.

**sleep paralysis** means the complete inability to move for 1 or 2 minutes immediately after awakening. It may also occur just before falling asleep.

**terminal event** means the proximate or ultimate cause of death and includes the following:

- (a) pneumonia;
- (b) respiratory failure;
- (c) cardiac arrest;
- (d) circulatory failure; or
- (e) cessation of brain function.

**VEA** means the *Veterans' Entitlements Act 1986*.