



Australian Government
Repatriation Medical Authority

Statement of Principles
concerning

NARCOLEPSY

No. 7 of 2014

for the purposes of the

Veterans' Entitlements Act 1986
and

Military Rehabilitation and Compensation Act 2004

Title

1. This Instrument may be cited as Statement of Principles concerning narcolepsy No. 7 of 2014.

Determination

2. The Repatriation Medical Authority under subsection **196B(2)** and **(8)** of the *Veterans' Entitlements Act 1986* (the VEA):
 - (a) revokes Instrument No. 57 of 2005 concerning narcolepsy; and
 - (b) determines in its place this Statement of Principles.

Kind of injury, disease or death

3.
 - (a) This Statement of Principles is about **narcolepsy** and **death from narcolepsy**.
 - (b) For the purposes of this Statement of Principles, "**narcolepsy**" means a sleep disorder manifested by recurrent periods of an irrepressible need to sleep, lapsing into sleep, or napping occurring within the same day. These periods of hypersomnolence must occur at least three times per week over a three month period and at least one of the following criteria must be present:
 - A. episodes of cataplexy, defined as either (i) or (ii), occurring at least a few times per month:

- (i) in individuals with long-standing disease, brief (seconds to minutes) episodes of sudden bilateral loss of muscle tone with maintained consciousness that are precipitated by laughter or joking; or
 - (ii) in children or in individuals within six months of onset, spontaneous grimaces or jaw-opening episodes with tongue thrusting or a global hypotonia, without any obvious emotional triggers;
- B. hypocretin deficiency, as measured using cerebrospinal fluid (CSF) hypocretin-1 immunoreactivity values (less than or equal to one-third of values obtained in healthy subjects tested using the same assay, or less than or equal to 110 picograms per millilitre). Low CSF levels of hypocretin-1 must not be observed in the context of acute brain injury, inflammation or infection; or
- C. nocturnal sleep polysomnography showing rapid eye movement (REM) sleep latency less than or equal to 15 minutes, or a multiple sleep latency test showing a mean sleep latency less than or equal to eight minutes and two or more sleep-onset REM periods.

This definition excludes narcolepsy due to another medical condition and sleepiness due to the direct physiological effects of a drug or medication.

- (c) Narcolepsy attracts ICD-10-AM code G47.4.
- (d) In the application of this Statement of Principles, the definition of "**narcolepsy**" is that given at paragraph 3(b) above.

Basis for determining the factors

- 4. The Repatriation Medical Authority is of the view that there is sound medical-scientific evidence that indicates that **narcolepsy** and **death from narcolepsy** can be related to relevant service rendered by veterans, members of Peacekeeping Forces, or members of the Forces under the VEA, or members under the *Military Rehabilitation and Compensation Act 2004* (the MRCA).

Factors that must be related to service

- 5. Subject to clause 7, at least one of the factors set out in clause 6 must be related to the relevant service rendered by the person.

Factors

- 6. The factor that must as a minimum exist before it can be said that a reasonable hypothesis has been raised connecting **narcolepsy** or **death from narcolepsy** with the circumstances of a person's relevant service is:
 - (a) having a moderate to severe traumatic brain injury within the two years before the clinical onset of narcolepsy; or

- (b) having concussion within the two years before the clinical onset of narcolepsy; or
- (c) having a surgical procedure which involves a craniotomy within the two years before the clinical onset of narcolepsy; or
- (d) having received a cumulative equivalent dose of at least ten sieverts of ionising radiation to the brain within the two years before the clinical onset of narcolepsy; or
- (e) undergoing a course of therapeutic radiation for cancer, where the brain was in the field of radiation, within the two years before the clinical onset of narcolepsy; or
- (f) having a specified neurological disorder with involvement in the region of the diencephalon or brainstem within the two years before the clinical onset of narcolepsy; or
- (g) receiving Pandemrix™, an adjuvanted influenza H1N1 vaccine, before the age of 40 years, within the three years before the clinical onset of narcolepsy; or
- (h) having a laboratory confirmed *Streptococcus pyogenes* infection within the three years before the clinical onset of narcolepsy; or
- (i) inability to obtain appropriate clinical management for narcolepsy.

Factors that apply only to material contribution or aggravation

7. Paragraph 6(i) applies only to material contribution to, or aggravation of, narcolepsy where the person's narcolepsy was suffered or contracted before or during (but not arising out of) the person's relevant service.

Inclusion of Statements of Principles

8. In this Statement of Principles if a relevant factor applies and that factor includes an injury or disease in respect of which there is a Statement of Principles then the factors in that last mentioned Statement of Principles apply in accordance with the terms of that Statement of Principles as in force from time to time.

Other definitions

9. For the purposes of this Statement of Principles:

"a specified neurological disorder" means:

- (a) a cerebrovascular accident;
- (b) a focal inflammatory lesion;
- (c) a neurodegenerative disorder, including dementia with Lewy bodies, multiple-system atrophy and progressive supranuclear palsy;
- (d) acute disseminated encephalomyelitis;
- (e) encephalitis;
- (f) hypothalamic-pituitary failure;
- (g) hypoxic cerebral insult;
- (h) intracranial space occupying lesion;
- (i) multiple sclerosis;

- (j) neuromyelitis optica;
- (k) parkinsonism;
- (l) Parkinson's disease;
- (m) Rasmussen's encephalitis; or
- (n) sarcoidosis;

"cumulative equivalent dose" means the total dose of ionising radiation received by the particular organ or tissue. The formula used to calculate the cumulative equivalent dose allows doses from multiple types of ionising radiation to be combined, by accounting for their differing biological effect. The unit of equivalent dose is the sievert. For the purposes of this Statement of Principles, the calculation of cumulative equivalent dose excludes doses received from normal background radiation, but includes therapeutic radiation, diagnostic radiation, cosmic radiation at high altitude, radiation from occupation-related sources and radiation from nuclear explosions or accidents;

"death from narcolepsy" in relation to a person includes death from a terminal event or condition that was contributed to by the person's narcolepsy;

"ICD-10-AM code" means a number assigned to a particular kind of injury or disease in The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), Eighth Edition, effective date of 1 July 2013, copyrighted by the Independent Hospital Pricing Authority, and having ISBN 978-1-74128-213-9;

"relevant service" means:

- (a) operational service under the VEA;
- (b) peacekeeping service under the VEA;
- (c) hazardous service under the VEA;
- (d) British nuclear test defence service under the VEA;
- (e) warlike service under the MRCA; or
- (f) non-warlike service under the MRCA;

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

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

Application

- 10.** This Instrument applies to all matters to which section 120A of the VEA or section 338 of the MRCA applies.

Date of effect

- 11.** This Instrument takes effect from 15 January 2014.

Dated this **nineteenth** day of **December** 2013

The Common Seal of the)
Repatriation Medical Authority)
was affixed at the direction of:)



PROFESSOR NICHOLAS SAUNDERS AO
CHAIRPERSON