

Feedback from Epilepsy Society of Australia and Australian and New Zealand Association of Neurologists on AFTD 2021 Draft and Interim Report

Roles & Responsibilities.

Table 2. The health professional's role is "To assess the person's fitness to drive based on relevant clinical and functional information and on the relevant published medical standards.", while the licensing authority's role is "To make all decisions regarding the licensing of drivers. The driver licensing authority will consider reports provided by health professionals, police and members of the public, as well as crash involvement and driving histories." We note that our suggestion to change the wording was rejected. The draft wording perpetuates the myth that it is the driver licensing authority that *in reality* (rather than in theory or even in law) makes the licensing decision because in most cases, the fitness assessment and the licensing decision are the same thing. It is misleading to state otherwise.

Our suggestion to add: "If the health professional becomes aware that information provided by the driver is unreliable, this should be communicated directly to the DLA." was not adopted nor the reason mentioned in the Review document. This is an important issue. Examples include drivers stating that they have had no seizures in the last year, despite medical records (which are now more accessible online) documenting Emergency Dept visits with seizures. However, it applies not only to people with seizures. Adopting our suggestion would provide doctors with guidance, would improve the likelihood of this vital information being brought to the notice of the licensing authority and provide the treating doctor with written support for their action. It should be added as a 4th bullet point to the following text in the Draft, which would then read:

"Health professionals should consider reporting directly to the driver licensing authority in situations where a patient is either:

- unable to appreciate the impact of their condition
- unable to take notice of the health professional's recommendations due to cognitive impairment, or
- continues driving despite appropriate advice and is likely to endanger the public, or
- provides information on their condition that is unreliable"

Another important situation we did not raise in our submission is the driver who has presented to an emergency department with a seizure and then fails to keep their appointment in the neurology clinic or follow-up with a GP. This was highlighted by the Coroner in her report of the inquest into the Ravenshoe crash (https://www.courts.qld.gov.au/_data/assets/pdf_file/0004/653242/cif-nyholtandclark-ravenshoe-20200626.pdf). A 5th bullet point should therefore be:

- fails to attend a specialist appointment or follow up with a GP after being advised to do so, following a medical episode that may be relevant to their ability to drive safely."

This is not uncommon, especially with seizures associated with substance abuse.

Blackout of uncertain nature causing a crash = default (12m)

Review: The advisory group thought that "there would be significant issues in practically applying this restriction due to the uncertainty surrounding the aetiology of these blackouts and challenges with accurately determining the occurrence and sequencing of the blackout and MVC."

Response: We do not understand why there would be issues in practically applying this restriction. Yes there are uncertainties in the diagnosis – in fact, uncertainty is essential to the definition of this situation. If this objection is valid, then it applies to the entire section. If the diagnosis in an individual became clear with time, the standard would, by definition, no longer apply.

We do not understand what is meant by “challenges with accurately determining the occurrence and sequencing of the blackout and MVC”. Does this mean that there is difficulty in determining whether the blackout caused the MVC or not? This is generally not difficult to determine (a crash occurs that the driver claims not to remember), regardless of uncertainty as to the mechanism of the blackout.

When the standard in this section was developed for AFTD 2016, it was modelled on the seizures section because a proportion of these drivers will actually have had a seizure or seizures. Omitting this part of the Blackouts standard makes it inconsistent with the Seizure standard.

We note that in the review document, Table 3.2.4 is titled “syncope/blackouts”. In fact, the table name should be “Blackouts of uncertain nature” (as it is in the Draft).

Although not included in our previous submissions, we note an unnecessary cross-reference/hyperlink that was present in AFTD 2016 that remains in the draft. We suggest changing “Refer also to section 1 Blackouts and section 2 Cardiovascular conditions.” to “Refer also to section 1 Blackouts”, as the Cardiovascular chapter is irrelevant.

We have based our comments on the text of the Draft document rather than the Review document, as there are some differences.

Terminology updates

6.2.1, paragraph 1. Please change both instances of “complex partial seizures” to “focal impaired awareness seizures”, as this terminology was changed in 2017 (Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology. Fisher RS et al. *Epilepsia* 2017).

Please change “or secondarily generalised with focal onset” to “or have a focal onset”.

We apologise for not suggesting this change in our submission.

Multiple places in text, figures and tables. Please change “antiepileptic medication” to “antiseizure medication”. (Another change from the International League Against Epilepsy)

6.2.2, paragraph 3. We note the change of wording in the draft from the AFTD 2016 wording: “Conditional licences rely on individual responsibility for management of the condition...” to “Conditional licences rely on individual responsibility for managing their condition...” The new syntax is not quite right, as it is the individual, not the conditional licence that has the condition. We suggest reverting to the 2016 wording or changing “individual” to “the individual’s”.

6.2.2, paragraph 4. We note that the following text in AFTD 2016 has been deleted “in addition, sleep deprivation is a common provoking factor in epilepsy and may be experienced in long-distance transport driving and amongst drivers doing shift work”. We do not know why this was deleted, as sleep deprivation is a very important provoking factor of seizures and it remains a fact of life that sleep deprivation occurs in some long distance truck drivers. We suggest restoring the deleted text.

6.2.2, Use of electroencephalograms. We suggest adding “(EEG)” in parentheses to the heading, as this abbreviation is used far more often than the full word. EEG is the abbreviation for both electroencephalogram (the recorded data of an individual’s brain waves) and

electroencephalography (the technique of recording an electroencephalogram). We suggest changing the opening words of the text of this paragraph from “Electroencephalogram (EEG) is” to “Electroencephalography (EEG) is”.

6.2.2, Advice to licence holders. To avoid inconsistency, we suggest adding the following text in parentheses after “Drivers of private vehicles who hold a conditional licence should be reviewed at least annually”: “(unless experiencing a prolonged period of seizure freedom – see *The default standard (all cases) on pxxx*.”

6.2.2, Other conditions with risk of seizure. Two typos: “are covered” should be “is covered”; “intercranial” should be “intracranial”.

6.2.3, ‘Safe’ seizures. para 3. The AFTD text was “...they may then be in a confused state and not appreciate the danger of resuming their journey.” In the current draft, “resuming” has been deleted. This is presumably a typo, as removal of this word inappropriately alters the meaning.

6.2.3 Resumption of an unconditional licence. The current wording does not cover resumption after a first seizure or acute symptomatic seizure. We suggest adding the following to the end of the current text “However, resumption of an unconditional private or commercial licence may be considered in some instances of first seizure or acute symptomatic seizures – see Table).”

Table. Medical standards for licensing (p136). We suggest inserting a hyperlink/cross reference to Figure 13. We also suggest inserting into each section of the table, hyperlinks to the corresponding section in the text part of the chapter (some already exist in the draft).

Table instructions. Step 2. In the text section re Seizure causing a crash or loss of control of a vehicle, and in the table, loss of control of the vehicle is mentioned (and is equivalent to a crash). For consistency, Step 2 instructions need to say this also. It should read: “Note that people are not eligible for a reduction if they have had a motor vehicle crash or lost control of a vehicle due to a seizure”.

Table instructions. Steps 1 and 2 instruct the doctor to read the “All cases” section and the “Possible reductions” section but do not instruct them to read the “Other factors” section of the table. This is important because a person may satisfy the standard according to the “Possible reductions” section of the table but fail to meet the standard to drive for one of the reasons in the “Other factors” section. We therefore suggest modifying Step 2 to indicate that it refers to the “Possible reductions” table and adding a Step 3 to instruct the doctor to check the “Other factors” table as well. The statement that refers to more than one standard applying, should follow Step 3. The complete instructions box would thus read:

“Step 1: Read ‘All cases’. This applies to all people with seizures.

Step 2: Look through the list of situations in the left-hand column of the *Possible reductions in the non-driving seizure-free periods for a conditional licence* table below to see if the person matches one of these situations. If so, the driver licensing authority may consider a conditional licence after a shorter (reduced) seizure-free period.

Step 3. Look through the left-hand column of the *Other factors that may influence licence status* table below to see if the person matches one of these situations.

If the situation is covered by more than one standard, the longer non-driving period applies. Note that people are not eligible for a reduction if they have had a motor vehicle crash or lost control of a vehicle due to a seizure within the preceding 12 months.

Health professionals should familiarise themselves with the information in this chapter and the tabulated standards before assessing a person's fitness to drive."

Text (p128) and Table. Default standard. Private and Commercial. Reduced review requirement in persons with very long seizure-free periods. We note that a submission requested guidance as to the appropriate interval between reviews in this situation. As mentioned in the Review document, 3-yearly reviews were suggested by us as reasonable and would satisfy many drivers in this situation who complain of unnecessary annual reviews. The Draft does not mention a period but has a hyperlink (3.3.7. Role of independent experts/panels) to information that is not helpful. We suggest replacing in both text and table "(refer to section 3.3.7. Role of independent experts/panels)" with "(a 3-yearly review may be appropriate in such drivers)". Otherwise, the current situation will continue, in which neither doctors nor driver licensing authorities have any guidance. In fact, there is little risk from even an inappropriately long review interval, as it would be extremely unlikely for a person experiencing their first seizure in over 10 years to wait until their next scheduled review to report it to their doctor or to realise that they should not drive until they do.

Table. First seizure. Commercial. When we suggested modifying the text to allow resumption of an unconditional licence, we accidentally omitted a bullet point from the commercial column. The paragraph in the commercial column should be: "Resumption of an unconditional licence...as to whether the following criteria are met:

- antiseizure medication has not been prescribed; and
- there have been no seizures for at least 10 years; and
- An EEG ..."

Table. Acute symptomatic seizures. Commercial. The same bullet point was omitted from the paragraph regarding resumption of an unconditional licence in the Commercial column. Apologies! Please insert it. The paragraph then reads

- antiseizure medication has not been prescribed; and
- there have been no seizures for at least 10 years; and
- An EEG ..."

Table. First seizure. Commercial. The advice that EEG is required only with the initial application for a conditional licence and not at annual review, should appear here (and not only in the Default standard). The 2nd bullet point should be:

- "an EEG conducted in the last 6 months has shown no epileptiform activity and no other EEG conducted in the last 12 months has shown epileptiform activity (this is only required for initial granting of the conditional licence and not for annual review);"

Please note that the words in parentheses are not required in the EEG bullet point that applies to resumption of an unconditional licence that follows in the table.

Table. Acute symptomatic seizures. Commercial. The same addition in parentheses needs to be made as for First seizure ("(this is only required for initial granting of the conditional licence and not for annual review)"). Again, this addition is not required in the EEG bullet point that applies to resumption of an unconditional licence that follows in the table.

Table. Epilepsy treated by surgery. Commercial. The same addition in parentheses needs to be made as for First seizure ("(this is only required for initial granting of the conditional licence and not for annual review)").

Table. Safe seizures. You have accepted our suggestion to add "Any seizures that involve confusion/vagueness, automatisms, difficulty speaking or emotional features or memory loss are not

considered safe seizures.” to the text but not to the table. The left hand column of the table is already crowded, so we would suggest simply adding (“See text pxxx”) at the end of the 1st sentence in the left hand column.

Table. Safe seizures and Sleep-only seizures. The words “or recommended” have been removed from the AFTD 2016 wording, which was “• the person follows medical advice, including adherence to medication if prescribed or recommended.” However they have not been removed from the Default standard or Exceptional cases standard. We assume this was accidental, as these words are necessary to clarify the situation in which a patient refuses treatment (which is especially liable to occur if the person believes, rightly or wrongly, that their seizures are safe).

Table Epilepsy treated by surgery. Private. The 2nd bullet point in AFTD 2016 has been deleted: “the person follows medical advice with respect to medication adherence.” This should not have been deleted, as some patients stop their medications prematurely after epilepsy surgery, in the optimistic belief that they have been cured. To make the wording consistent with the rest of the table, it could be re-worded as “the person follows medical advice, including adherence to medication.”

Table. Unreliable or doubtful clinical information. Private and Commercial columns. A comma has been removed between “seizures” and “likely”, which changes the meaning slightly. We suggest reinstating the comma, so it reads: “Where the reliability of relevant clinical information is not clear (e.g. unreported seizures, likely due to the person not recognising...”. Of more importance, you have accepted our suggested text: “...the person is not fit to hold an unconditional licence.” While this is true, it may imply that the person is fit to hold a conditional licence (but they are not). We should have instead suggested “...the person is not fit to drive.” and suggest this now.

Table. Recommended reduction in dosage. Private and Commercial. The word “current” has been removed from the AFTD 2016 wording, which was “...if the dose reduction is due only to the presence of current dose-related side effects”. This word was added in 2016 to clarify that reducing a dose to avoid *potential* side-effects is not a reason to allow continued driving. Rather, the patient has to be having side-effects *now*. We suggest reinserting this word.

Table. Resumption of an unconditional licence. Commercial. Suggest adding to existing text, the following words in parentheses. The text would then read: “Resumption of an unconditional commercial licence will not be considered (except in some instances of first seizure or acute symptomatic seizure – see above).”

Hypoglycaemic seizures – conflict between Diabetes and Seizure standards. It was noted during preparation of AFTD 2016 that seizures due to hypoglycaemia required a minimum non-driving period of 6 weeks according to the Diabetes standards and 6 months according to the Seizure standards (Hypoglycaemic seizures are an example of acute symptomatic seizures). A teleconference was held between endocrinologist and neurologist representatives but agreement was not reached. We note that this inconsistency continues in the Draft.

Psychogenic non-epileptic events (“seizures”). We note also that the issue of psychogenic non-epileptic events has not been finalised.