09 February 2018

Australian Government Productivity Commission

I am sorry to have missed the opportunity to input into the review of the DVA earlier.

I have just become aware of the review and have scanned the draft report over the last few hours and thus this submission is to make the deadline of 11 Feb 19. I therefore apologise with the somewhat rushed nature of this submission and its poor prose and syntax.

My concerns relate predominantly with the Statement of Principles (SOPs) and the Repatriation Medical Authority (RMA). I note the element of your report which covers this.

Specifically, I note the sections that states:

- *Each SoP defines a specific condition, typically with reference to common symptoms. They also outline a set of causal 'factors' for that condition, at least one of which must be linked to a veteran's service to establish a causal connection. Each factor contains an event (such as 'experiencing a significant physical force applied to or through the affected joint' or 'being bitten by a mosquito') and a time period between that event and clinical onset or worsening of the condition (for example, 'at the time of clinical onset/worsening' or 'within the two years before clinical onset/worsening').*
- *The SoPs are binding for decisions about liability for conditions made under the VEA and MRCA (but not DRCA) for all decision makers, from DVA through to the federal court system. This means that a hypothesised link between the claimant's condition and service must be supported by at least one factor in the relevant SoP before it can be accepted.*
- *Claims assessors are not able to accept a claim that makes a hypothesis linking a veteran's condition to their service through a factor that is not included in an existing SoP. As Creyke and Sutherland noted:*
- *The decision-maker cannot use the evidence of an expert or others to contradict or provide alternate scientific or other facts to those in the relevant SoP. An hypothesis that does not fit within the template will not be 'reasonable' and the claim must fail. (2016, p. 433).*
- *The RMA is bound by legislation to only incorporate existing evidence into the SoPs. For novel diseases or causal links, there may be no, or only poor quality, peer-reviewed medical evidence. As William Gore questioned, 'the RMA requires the rigour of scientific evidence before it can promulgate a factor, however, if the science is not available, what then?' (sub. 97, p. 1).*
- *Without adequate sound medical-scientific evidence, the RMA will not include a hypothesised link between the condition and the service in the relevant SoP. The RMA treats strong evidence that there is no causal link (Grade 5b) the same as an absence*

of solid evidence that there is a causal link (Grade 5a), both of which are insufficient for including a factor in the relevant SoP under either standard of proof (section 8.1).

- *Conceivably, the testimony of only a few specialists may be sufficient to provide 'sound medical-scientific evidence' of a reasonable hypothesis under the clinical judgment clause.*
- *In practice, however, the RMA seldom relies on the clinical judgment clause in isolation, using it only when there is no sufficient epidemiological evidence in the literature (Donald 2008). Although this reliance on peer-reviewed literature is reasonable, participants to this inquiry identified two broad areas of concern:*
    - *where the medical-scientific evidence is new or only just emerging, such that there has not yet been extensive peer-reviewed research*
    - *where the veteran population diverges from the civilian population, such that a reliance on civilian peer-reviewed literature can lead to different outcomes."*

<u>The treatment of emerging medical-scientific evidence</u>

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- *Without adequate sound medical-scientific evidence, the RMA will not include a hypothesised link between the condition and the service in the relevant SoP. The RMA treats strong evidence that there is no causal link (Grade 5b) the same as an absence of solid evidence that there is a causal link (Grade 5a), both of which are insufficient for including a factor in the relevant SoP under either standard of proof (section 8.1).*
- *One reason for equating inadequate evidence of any link with strong evidence of no link is that the lack of sufficient evidence (whether peer-reviewed scientific literature or even indicative case reports) is a result of the causal link being spurious or unsound — there may not be a lot of peer-reviewed research into the direct causal relationship between head trauma and developing frostbite, for example, because such a relationship is highly unlikely to exist. As such, a lack of high-quality studies can be indicative of no causal relationship existing.*
- *However, an alternative is that the hypothesised link between the service and the condition is legitimate, but as yet, is simply unsupported by any research — after all, an absence of evidence is not the same as evidence of an absence.*

This is exactly the issue I have confronted and failed have resolved with the RMA or DVA. I spent some 40 years 3 months serving in the Royal Australian Navy (RAN). My interviews and medicals to join were conducted in 1975 at the age of 15 and I joined the Navy at the age of 16. I discharged from the Navy at the age of 56, in 2016.

I agree completely with, and wish to add my strong support to the following statement in the draft report:

- *A number of participants said that the SoPs should be applied more flexibly — that is, claimants should be able to present evidence of a hypothesis that is outside of the strict bounds of the relevant SoP factors. This includes hypothesising new causal factors that*

are not included in the SoP, as well as allowing more flexibility on the exposure levels or latency time periods between exposure and onset that are currently within the SoPs. Some said that the SoPs should only be a 'guide' for assessors, rather than a strict checklist (Kenneth Park, sub. 2; Slater + Gordon, sub. 68; Maurice Blackburn, sub. 82; Legacy Australia, sub. 100; Legal Aid NSW, sub. 109; DFWA, sub. 118).

As part of my preparation for discharge, I perused my medical documents, covering as they did 40 years of my life, and with the help of an RSL Advocate I submitted my claims. Some were accepted, some were not.

It became apparent to me through personal meetings with senior personnel in DVA, Craig Orme and Dr Ian Gardner, that they and others in the DVA are doing excellent jobs. They explained in detail to me the difference between causation and association and how those terms are focused in on by DVA when determining a specific claim.

Some of my conditions were accepted and others weren't. I chose not to appeal the decision at the time, as I understood that any one of numerous case managers would make the same decision, as all they are bound by the specific SOP. My issue is therefore not with case managers, nor the senior administrative leadership of the DVA, but rather with the way that SOPs are written, legislated upon and reviewed.

Unfortunately, I contracted Chronic Lymphocytic Leukaemia (CLL) during my 40 years in the RAN. It was picked up via a full bloods test in 2012, at the age of 52, but I had had bad night sweats as far back as 2002, so in retrospect that might have been the initial onset of the virus. My initial Medical Employment Classification (MEC) was determined by Navy to be MEC 4: Employment Transition. I argued this via an appeal, but Navy changed their determination prior to the formal appeal and I spent the last four years of service as MEC 2: Employable and Deployable with Restrictions.

At the time when the Department refused any liability for my CLL, I had already been involved with the Repatriation Medical Authority (RMA), as I had challenged their determination that the only cause of CLL was "being exposed to Benzene". I had excellent medical evidence from the USA, where I had spent my last three years of service and from the expert Oncologist who treated me for the CLL during my time in the USA.

I attach that letter, and one or two other documents to do with the causes of CLL at the end of this submission: I also note that I provided much additional evidence to the RMA – all of which they dismissed.

My details are all on file at the DVA, as should be my letter and correspondence with the RMA, specifically its head, Professor Saunders. Despite my entreaties, the SOP was not modified and although I am grateful that my ongoing treatment is covered by my White Card, the fact that the Department refuses to acknowledge that any of my extensive 40 year, virtually life-long service, may have contributed to my contracting CLL is hard to believe.

I write this because under the recommendations of the Parliament of the Commonwealth of Australia, Inquiry of the Defence Sub-Committee conducted by the Joint Standing Committee

of Foreign Affairs, Defence and Trade in June 2013 on the "Care of ADF Personnel Wounded and Injured on Operations", the Committee, under Recommendation 23, recommended that DVA:

- Review the SOPs in conjunction with the RMA with a view to being less prescriptive and allowing greater flexibility to allow entitlements and compensation related to service to be accepted.
- Periodically publish reports measuring success in adhering to their client service model.
- Periodically publish claim processing times, and
- Periodically publish claim success rates.

Now I have no idea if DVA is doing the last three. It is certainly not on their website. But I can tell you that my 2016 experience with the RMA definitely shows that the RMA is not doing the first. Indeed, the SOP was so restricted, that despite there being no new medical evidence to support their new SOP, they have made it so restrictive that it is virtually impossible for an ADF person with CLL to reasonably make a case. ***(Last September I did re-submit my CLL claim, based on Benzene exposure – and I am still awaiting a decision)*** I must therefore conclude that the RMA has gone against the recommendations of the Joint Standing Committee.

I am also concerned that the ADF is all too often looked at as being a homogenous workplace. However, Navy, Army and Air Force a very, very different when it comes to exposure to accidents, injury and hazards. Each service has its particular hazards, but service in the Navy is more hazardous on a more continuous basis, because we live and work at sea in an industrial workplace. Army and Air Force have their extremely hazardous periods, but their accommodation in the normal course of their employment is not an active work site. Without getting into too much detail, here are some pertinent facts:

- In Navy, when at sea:
    - our home is an industrial work site, all the time, often for many months continuously.
    - Such a home is inculcated virtually continuously with radiation from transmitters and radars, not just from your own ship, but also those in company, some of whom are foreign navies with different levels of safety and control of harmful radiation.
    - It rocks and rolls.
    - It is noisy and uncomfortable and it is 24 hours a day, seven days a week.
    - We conduct endless damage control exercises, where we use practice smoke to simulate fire and we use aqueous film forming foams and other chemical agents.
    - We conduct numerous fuelling evolutions while underway, but we don't count hours, which is something the RMA seems fixated on.
    - In my early years the paints we used were heavy in Lead/Zinc Chromate and the ships were filled with asbestos.
    - Even our uniforms are made from a formalydehyde substance – proban.
    - There are the normal hazards of oily sludge, diesel exhausts and the daily issues of serving for extended periods at sea.

However, when I challenged the RMA on the SOP and my CLL, via a review of the SOP, and asked why they had rescinded their previous SOP determination, especially at a time when medical-scientific evidence, both in the USA and Australia was expanding it, the standard line was that:

"The RMA however, does not deal with individual claims, but determines SOPs which set out all of the potential causes (factors) that can cause or worsen a particular injury, disease or death – at least one of which must as a minimum exist to establish a causal connection for the condition with the circumstances of an individual's service."

Here, in a single paragraph is the hub of much dissatisfaction with decisions attributed to case managers and the DVA – the problem is really with the SOPs and therefore with determinations by and the approach of, the RMA. As the DVA moves to become a client focused agency it is hamstrung by a RMA which still adheres to narrow, causal factors in their SOPs. It also appears to me that the RMA has failed to heed the recommendations from June 2013, made by the Joint Standing Committee. If anything, certainly with CLL, the RMA has been at pains to go the other way, reducing flexibility to zero and asking for hours of exposure to benzene as the only causal factor.

There is not a single Oncologist who has treated me, neither the two in Australia, nor my one in the USA, who can say with any certainty what causes CLL. My treating Oncologists/ Haematologists have written that the RMA's restrictive focus on the use of benzene, and especially the hours of exposure, to be a most unusual way to determine the minimum threshold to determine beyond a reasonable hypothesis that there is a link.

Indeed, without repeating the details of my extensive correspondence with the RMA in 2015 and 2016 a key US study[1] did state in May 2015 that:

- The molecular pathogenesis of CLL is a complex, multistep process leading to the replication of a malignant clone of B-lymphocytes. While some steps in this pathway have been elucidated, many remain unknown. It is believed that virtually all CLL cases are preceded by a premalignant B cell proliferative disorder known as monoclonal B cell lymphocytosis (MBL).
- Establishment of MBL – While the inciting event is unknown, MBL appears to develop as the result of multiple factors, such as response to antigenic stimulation[2], micro environmental support, gene mutations, epigenetic modifications[3], and cytogenetic abnormalities[4]. The result is a clone of B cells with a CLL phenotype.
- Progression from MBL to CLL – Further insults to the B cell clone, either through additional genetic abnormalities or changes to the bone marrow microenvironment, result in the

[1] 12 May 2015 by Kanti, R Rai, MD and Stephan Stilgenbauer, MD titled "Pathophysiology and Genetic Features of Chronic Lymphocytic Leukaemia".

[2] Antigen" is short for "antibody-generating," or basically any substance that causes the body to produce antibodies.

[3] Epigenetic change is a regular and natural occurrence but can also be influenced by several factors including age, the environment/lifestyle, and disease state.

[4] Chromosome anomalies usually occur when there is an error in cell division following meiosis or mitosis.

progression of MBL to CLL. This progression occurs in a very minor portion of persons with MBL.

- B cell antigen receptor (BCR) stereotypy in CLL cases suggests a role for antigens in the pathogenesis and evolution of CLL.

In discussions with my treating US Oncologist he advised that the factors that the RMA has used as the minimum required under SOP 084-2014 bear little or no basis in medical fact. The latest US studies clearly show that MBL preceded CLL in the vast majority of cases and that the causal factors of CLL are much broader than RMA's narrow definition based on extensive benzene exposure alone.

When I provided this to the RMA in late 2015, they refused to countenance this. They did conduct a review of the SOP, but the review was limited to" an investigation in respect to the definition "being exposed to benzene." This was completely unhelpful and still to the best of my knowledge is not supported by the latest medical research on CLL.

My point is that, if the policies of the DVA are interpreted so narrowly and inflexibly by the RMA, the ability of the DVA to truly be 'client focused' will indeed be almost impossible to achieve. After spending my life, from the age of 16 to 56 in the Navy, my view is that if the DVA is serious about being client focused it needs to become a little more flexible with its SOPs, not more restrictive as the RMA has done with CLL.

I therefore disagree with your finding that:

- *The SoP system also works well for the vast majority of cases, creating decisions based on an expert analysis of the latest sound medical-scientific evidence. Some individual cases will not succeed, but this is because there is a necessary line drawn between liable and non-liable claims, not because of any underlying issue with the system. The Commission is not convinced that there should be more flexibility in the SoP regime, as allowing it is likely to undermine the system.*

In the case of diseases such as leukaemia with uncertain and disputed causes, flexibility must be included, and the RMA must be more heavily scrutinised, especially where the working and living conditions in prolonged sea-service in the Navy, is so completely different to any found in civilian life. 40 years of service, an uncertain date of onset of CLL (probably 2002) and I am just told no by the RMA – really, really, really poor.

I note your:

INFORMATION REQUEST 8.1

- *The Statements of Principles are created on two different standards of proof for the underlying medical-scientific evidence — a 'reasonable hypothesis standard' and a 'balance of probabilities' standard.*

- *The Commission is seeking participants' views on which standard of proof the veteran support system should use going forward. What would be the impacts of that choice on future claims and government expenditure, and how could they be quantified?*

Based on my experience, I believe that a standard of proof based on "association" rather than "causation" is more equitable. Therefore, I am of the mind to support the "reasonable hypothesis standard". However, I am firm that the RMA's extremely narrow and legalistic definition in SOPs that cover diseases of uncertain or conflicted causation is an area of failure in the system, as is their dismissal of expert treating Oncologist submissions, especially where the treating Oncologist has been treating a patient for years – thus no "doctor shopping" at all.

I agree with your

DRAFT RECOMMENDATION 8.2

- *The Australian Government should amend the Veterans' Entitlements Act 1986 (VEA) to allow the Repatriation Medical Authority (RMA) the legal and financial capacity to fund and guide medical and epidemiological research into unique veteran health issues, such as through a research trust fund.*
- *Following any investigation, the RMA should be required to publish the list of peer-reviewed literature or other sound medical-scientific evidence used, as well as outline how different pieces of evidence were assessed and weighed against each other. This may require legislative amendments to the VEA.*
- *Additional resources should also be given to the RMA, so that the time taken to conduct reviews and investigations can be reduced to around six months.*

INFORMATION REQUEST 8.2

- *The Commission is seeking participants' views on whether there is merit in the Specialist Medical Review Council remaining as a standalone organisation, or whether its role should be folded into an augmented Repatriation Medical Authority review process that brings in additional medical specialists.*

Based on my experience of trying (and failing) to get an amendment to a SoP through the RMA, I would support the SMRC being folded into an augmented RMA. The RMA as it currently is has no Oncologist/Haematologist in its members, but is very comfortable refuting evidence placed in front of it by eminent Oncologists/Haematologists. Any change that improves this current system is welcomed by me.

I would also like to make a comment on the section you have written on "Transition from the Services to civilian life." My view, especially after 40 years of service, is that the imposition of a 12-month limit to access entitlements such as a removal, re-training or a job, is far too restrictive. In my case, especially with my medical conditions, it took me about 18 months to two years to really understand my mental and physical state and then to start to plan where we might live and what I may do. By then I was not entitled to any support by or from Defence. My strong view is that veterans with many years of service should be afforded much longer than 1 year. I read in your draft report that Canada has a 10-year timeframe – makes much more sense to me.

I apologise, again, for the rushed nature of this input. I welcome your review

Yours sincerely,

Richard Menhinick, AM, CSC