

Comment by Denis Strangman AM on Consultation Paper “Early Release of Superannuation Benefits”.

Denis Strangman AM. [REDACTED].

Background: The author was a co-founder of Brain Tumour Australia and Brain Tumour Alliance Australia, and co-founder and Foundation Chair (2005-2014) of the International Brain Tumour Alliance. His wife was diagnosed with a malignant, primary brain tumour (a glioblastoma Grade 4) in 2000 and died 11 months later in 2001. He attends meetings of the ACT brain tumour support group and participates in various on-line and Facebook groups for brain tumour patients. He lives in an independent living unit in the Calvary Haydon Retirement Centre with an income based on the lowest available payment of the age pension and a Commonwealth Superannuation Pension based on 32 years’ of contributions and is therefore both an aged pensioner and a superannuant.

Below are three proposed guiding principles for this review.

- **Preservation:** Superannuation benefits should generally be preserved to provide income in retirement to substitute or supplement the Age Pension. Early access to superannuation for other purposes is inconsistent with the preservation principle.
- **Genuine hardship:** There will be circumstances where the benefits of early access to superannuation for an individual will exceed the benefits of preserving balances until retirement. The challenge for policy-makers is to identify the point at which the need for compassion outweighs the broader policy objective of the superannuation system.
- **Last resort:** Early release of superannuation benefits should generally be a last resort where other sources of financial support have been exhausted. It is not an appropriate replacement for existing health and income support policies.
- **Fair and effective:** The rules should be able to be administered fairly and effectively; that is, the rules should be sufficiently clear and objective to allow applications to be dealt with in a timely and consistent fashion, and ensure that similar cases can be treated alike. Rules that are highly subjective in nature will necessarily cause more red tape, expense and difficulty for applicants, trustees and Government.

QUESTIONS

0.1. Do these proposed principles provide an appropriate guide to determine the nature and scope of the rules for early release under compassionate and financial hardship grounds, and for victims of crime compensation? If no, what should the principles be?

0.2. Having regard to these principles, should early release of superannuation benefits generally be more or less difficult to obtain?

Comment: There appear to be four guiding principles. In relation to the **first proposed guiding principle**, the following words could be deleted “Early access to

superannuation for other purposes is inconsistent with the preservation principle.” They are gratuitous, unnecessary, and are evidence of a pre-conceived stance. I agree with the **second proposed guiding principle**. These words could be deleted from the **third proposed guiding principle** “... where other sources of financial support have been exhausted”. The wording is too broad and could include a situation in which an over-zealous ATO official required an applicant to approach other family members for financial assistance, or required the applicant (if they are a carer or spouse) to realise on assets that involve a substantial loss in their accumulated value e.g. selling shares. I tend to agree, hesitatingly, with the **fourth proposed guiding principle**.

My answer to Question 01 is No, for the reasons outlined above.

My answer to Question 02 is “about the same”.

QUESTION 1.1 Should the assessment of financial capacity be made more prescriptive and/or objective? If so, how? What information might applicants need to provide?

Comment: Assessments should always be objective but overly-prescriptive procedures can be very stressful to families when they are faced with a fast-developing malignancy (e.g. a malignant primary brain tumour) which is associated with other stressors of a non-financial nature.

QUESTIONS

1.2 What factors might be driving the increase in the amount of superannuation released on medical grounds and are these factors any cause for concern?

1.3 Do the current provisions for early release on medical grounds strike the appropriate balance between preserving income for retirement and providing assistance in times of genuine hardship? If no, what are the alternatives?

1.4 Should there be a limit on the number of releases permitted within a certain timeframe (for example, 12 months) and/or should there be cashing restrictions on the amount released? If so, should there be different restrictions for different medical conditions?

Comment: My experience is based on extensive observations of what has been happening in the brain tumour community. Many of the patients who seek early access to their superannuation are suffering from a malignant primary brain tumour whose general prognosis has not altered greatly in the past thirty years (See, for example, the report by Senator Bilyk’s Committee into low survival cancers.)¹

At the time of my late wife’s diagnosis she was the first patient in the ACT to receive what was then the new treatment of radiation therapy and temozolomide, which has later become the standard of care for glioblastoma patients. She received the temozolomide, at subsidised rates, via the Canberra Hospital. I am not sure if this

¹https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Funding_for_Research_into_Cancers/FundingResearchCancers/Report

was because it was available as part of a clinical trial, or because the Hospital subsidised its provision, or because the relevant pharmaceutical company provided it for free.

I was involved with a later successful approach for the therapy's subsidisation under the PBS. This occurred during Mr Abbott's time as Health Minister. I am not sure what I might have done during 2000-2001 had the drug only been available at a high cost. I had been observing its growing emergence as the standard of care for this particular type of brain tumour and had been in contact with overseas neuro-oncologists about its efficacy. *The official results of the seminal clinical trial were not published until four years after my wife's death.*² At the time of my late wife's illness I had taken early retirement and we were living on my Commonwealth Public Service superannuation pension.

I make the point that if one waits for publication of a definitive clinical trial as an eligibility requirement for access then this could be several years after the brain tumour patient has died. This is why brain tumour patients – unlike those who suffer from other less deadly cancers with a better prognosis – are anxious to access the latest emerging therapies which have an indication of efficacy, so that their overall survival might be extended. That is why they often seek early access to their superannuation.

I have observed many promising brain tumour therapies in the past 17 years as a patient advocate and even though some of them showed promise at a phase 2 clinical trial level they have mostly failed.

At the stage when they showed promise they could only be accessed as part of a clinical trial, or at great expense because they were unsubsidised and represented a price based on recovery by the pharmaceutical company of its research investment.

Bearing in mind the poor prognosis (11 months in my wife's case) I do not blame patients who tried to access these expensive therapies in order to extend their likely survival.

In the past 17 years I have seen only one other therapy available in Australia that showed very promising early evidence of efficacy. This has been Avastin, or bevacizumab. Its promise has not eventuated but it remains relevant as a therapy that can reduce brain swelling (a common side effect of a brain tumour) and as a combination therapy (in conjunction with another therapy). The pharmaceutical company that holds the distribution rights in Australia has a special access scheme that requires the patient to pay for the first five treatments (approximately \$20,000) and then it will provide the drug for free, providing it shows continuing efficacy.

Many patients have problems in providing that required \$20,000 and may seek access to their superannuation for that purpose. They might also seek access at an earlier or later stage to superannuation monies to pay for private neurosurgery by a

² <https://www.ncbi.nlm.nih.gov/pubmed/15758009> Stupp R, Mason WP, van den Bent MJ et-al. Radiotherapy plus concomitant and adjuvant temozolomide for glioblastoma. N. Engl. J. Med. 2005;352 (10): 987-96.

particular neurosurgeon. That might include the insertion of Gliadel wafers at the time of neurosurgery which could represent an additional expense.

Other patients may wish to travel overseas to access a neurosurgeon who either has more experience with their particular type of tumour, or who might be combining an experimental therapy with surgery.

The needs of the brain tumour patient might therefore be varied and episodic *and require a number of requests.*

Another process which might require repeated requests involves the expensive, unsubsidised process of **genetic testing** to determine characteristics of the patient's tumour. My understanding is that each round of comprehensive tests might cost approximately \$2,000. This testing is even more necessary because of the emergence of the identification of brain tumours by their genetic characteristics as a result of the revised WHO classification of brain tumours, and the direction of research related to the development of personalised therapies which target specific molecular characteristics.

My response to **Question 1.2** is contained in the above comments. As far as patients with a malignant primary brain tumour are concerned, any increase in numbers is probably attributable to increased knowledge of the availability of the scheme and the failure of other components of their treatment and care to extend survival as a result of an affordable cost.

My response to **Question 1.3** is that the "current provisions" appear to be working appropriately because of the absence of anecdotal information about any difficulties in obtaining access. I do not place as much emphasis on preserving income for retirement as others might.

My response to **Question 1.4** is that there should be no limit to the number of releases, apart from limits to generally-agreed frivolous applications, because of the episodic nature of the course of the disease (i.e. a malignant primary brain tumour) and the possible emergence of promising new therapies with little or no advance notice.

QUESTIONS

1.5 Have you observed any trends in the types of treatments that are being funded by superannuation benefits and are these trends any cause for concern?

1.6 Are there certain treatments for which early release of superannuation should not be permitted? If so, what is the basis upon which these treatments should be excluded?

1.7 When might ART (IVF) be necessary to treat a life threatening illness or alleviate acute or chronic pain or mental disturbance (in general – noting that this will depend upon the specific circumstances of each case)?

1.8 When might bariatric surgery be genuinely necessary to treat a life threatening illness or alleviate acute or chronic pain or mental disturbance (in general – noting that this will depend upon the specific circumstances of each case)?

1.9 Should the rules explicitly require that the Regulator be satisfied that the amount claimed for a particular treatment is ‘reasonable’? If so, what evidence might be relevant to that determination?

Questions 1.5, 1.6, and 1.8 – No comment.

Question 1.7 I am not medically qualified but I read the relevant literature and have received the annual public service award from the US-based Society for Neuro-oncology, which is the professional body for those involved with brain tumour research and treatments. I do not understand the way in which IVF might “be necessary to treat a life threatening illness” and have not come across this claim in my interaction with the brain tumour community.

Question 1.9 The rules should be flexible in determining what amount is “reasonable”, otherwise a bureaucratic and time-delaying process might be introduced to the distress of the patient and their family.

Question 1.10 – No comment.

QUESTION

1.11 Should SIS Regulation 6.19A(3)(a)(ii) and (iii) be amended to refer to ‘treatment’ rather than ‘alleviation’ of acute or chronic pain? Alternatively, should those provisions be removed entirely (so that early access is only available where the individual’s condition is life-threatening)? What would be the consequences of this approach?

Question 1.11 – This question is difficult to understand and to answer. My concern is that those patients with a malignant primary brain tumour continue to have early access to superannuation. They do not often experience “acute or chronic pain” but do suffer mental distress at the realisation they have a terminal illness with a very poor prognosis.

QUESTIONS

1.12 Should the reference to a medical specialist in SIS Regulation 6.19A(3) be clarified to ensure that the practitioner is a specialist in the field most relevant to the condition being treated?

1.13 Should the Regulator be entitled to seek a second opinion from an approved medical practitioner/s, or should the individual be required to obtain a reference from a list of approved medical practitioners, to ensure the objectiveness of the assessment?

Question 1.12 – Comment – Yes. I am aware that in an original draft of the Mental Health legislation in the ACT the drafters appeared to consider a psychiatrist as having a capacity to perform neurosurgery.³

³ See: <http://www.legislation.act.gov.au/a/2015-38/current/pdf/2015-38.pdf> In its original loosely-worded form (Section 61 of the Bill) Section 169 implied that a psychiatrist could undertake the

I am also aware that some specialists can be tardy in their provision of required authorisations. I found this to be the case in advocacy for access to travel insurance for people with a malignant primary brain tumour. The insurance body believed that a letter supporting a person's travel might be helpful to an insurance company in determining its acceptance of the patient as a client for coverage. This suggestion was conveyed to the relevant professional organisations but I am not aware that many such letters eventuated.

Question 1.13 – Comment – No. See above comments about the tardiness of some specialists in providing relevant statements. There is also the practical aspect in regard to those with a primary malignant brain tumour that the specialist sometimes seeks to preserve hope on the part of their patient by minimising discussion of the precise terminal nature of their illness. It is therefore not desirable to have the patient canvassing for a specialist who might write in the most dire of language for purposes of supporting early access.

QUESTIONS

1.14 Should early access to superannuation benefits to meet expenses associated with palliative care, death, funeral or burial be limited to where there is a dependency relationship? Why/why not? Could there be any unintended consequences from expanding this provision?

1.15 Should there be a maximum amount that can be released to meet a funeral expense? (For example, the amount that the Regulator considers reasonable).

Question 1.14 – Comment – No. “Dependency” can have a rather precise and limiting application which could work against the exercise of compassion in a real situation. The example is given in the discussion paper of contributions towards the costs incurred by a non-dependant e.g. a parent. The median age for diagnosis of someone with a glioblastoma is 64 years and while the tragic situation of a paediatric patient often receives most media the actual situation for hundreds of Australian families each year is that it is someone in their ‘fifties or ‘sixties whose life is cut short by the diagnosis of a glioblastoma brain tumour. Siblings or adult children should have the opportunity to contribute towards the funeral or palliative care of an adult brother or sister or parent.

Question 1.15 – Comment – While I am initially inclined to say No, I could envisage a situation where a claim was made for an entirely outrageous amount beyond “reasonable” expectations and therefore, there should be a limiting factor.

Questions 1.16 and 1.17 (Mortgage payments) – No comment.

QUESTIONS

1.18 Are the current disability grounds fit for purpose, or should early release be extended, for example, to disability aids? If the latter, which expenses should be included, what evidence should be required, and should there be a cap on funds released?

neurosurgery in the case of psychiatric surgery. I made representations about this absurdity and the relevant section of the Act no longer contains the ambiguous wording.

1.19 Should individuals seeking early release of superannuation under disability grounds be required to demonstrate that they have sought assistance from other Government or non-Government programs prior to being approved? If so, how should this requirement be administered?

Question 1.18 – Comment – In regard to a glioblastoma patient and, say, a motor scooter, and their possessing it for the “long term”, everything is relative and while the patient might gain immediate benefit and relative independence through possessing it, the possession is not likely to be “long term” when they have a disease with an average prognosis of about 15 months.

Early release should be extended and the insistence of a correlation with a long-term benefit is unrealistic.

Question 1.19 – Comment – No. The NDIS is not intended to cover assistance which is available through other Government schemes and therefore any applicant will have experienced that requirement. Because of my involvement as a volunteer carer peer support worker in the Mental Health area I have witnessed the problematic experience of applicants for NDIS assistance. Superannuation applicants suffering from a glioblastoma should have the freedom to choose to access their superannuation monies even though they might have had a “theoretical eligibility” via the NDIS.

QUESTION

1.20 Should the Regulator’s residual discretion in SIS Regulation 6.19A(1)(f) be removed? What would be the consequence of doing so?

Question 1.20 – Comment – No, it should be retained. The operation of the scheme should be weighted in favour of the applicant, particularly in the case of glioblastoma patients who are often suffering a high burden of stress due to the terminal nature of their illness.

Questions 1.21 and 1.22 – No comment.

QUESTIONS

2.1 Having regard to the necessary trade-off between simplicity, objectivity and flexibility, should the criteria for severe financial hardship be amended? If so, how? In particular, is there merit in expanding or contracting the 26-week rule and/or the definition of qualifying Commonwealth income support payments?

2.2 Should there be a prescribed standard of proof of being ‘unable to meet reasonable and immediate family living expenses’? How can the legislation guard against non-genuine claims?

Questions 2.1 and 2.2 – Comment – In so far as I understand the background information in the consultation paper, any amendments to the periods required for eligibility should take into account the poor prognosis and the rapid deterioration of the glioblastoma patient. The eligibility periods mentioned appear, on the surface, to be too stringent.

Questions in Part 3 – I have no comment on these questions.