



8 November 2023

Jim Chalmers  
Treasurer of Australia  
Australian Government

&

Ms Carol Austin & Mr Nathan Dal Bon  
Executive Leaders  
Housing Australia

**By Email: Special request to consider expanding the focused beneficiary demographics within the *Housing Australia Investment Mandate Amendment (Social Housing, Affordable Housing and Acute Housing Needs) Direction 2023*, to include youth.**

Dear Mr Chalmers, Ms Austin, Mr Dal Bon, and representatives of The Treasury,

On behalf of Sony Foundation Australia ('Sony Foundation'), please accept our special request to consider expanding the focused beneficiary demographics within the *Housing Australia Investment Mandate Amendment (Social Housing, Affordable Housing and Acute Housing Needs) Direction 2023*, to include youth, with a focus on the acute housing/accommodation needs of youth with disability.

By way of introduction, Sony Foundation is a charitable organisation registered with the Australian Charities and Not-for-profit Commission. Sony Foundation is the charity arm of the Sony Group of Companies operating within Australia. Sony Foundation's mission is to improve the health and well-being of young Australians in need. Sony Foundation takes on the big issues, ones that are often underfunded, through corporate philanthropy and collaboration, creating positive experiences and championing equitable health and well-being outcomes for Australian youth.

In June 2010, Sony Foundation established 'You Can' in response to the alarming findings of a Senate Inquiry into Australian cancer care, which highlighted the disparities in health and well-being outcomes of youth with a cancer diagnosis when compared to that of their paediatric and adult counterparts.

- More 15-25-year-olds (youth) are diagnosed with cancer than children each year, yet their specific needs can often be overlooked.<sup>i</sup>
- Growing evidence that cancers in young people have a unique biology,<sup>ii</sup> as well as recognition that young people with cancer have a distinct medical, psychosocial and information needs.<sup>iii</sup>
- Youth cancer patients are six times more likely to experience mental ill-health, including high levels of anxiety, depression and/or Post-Traumatic Stress Disorder, following their treatment and for years to come.<sup>iv</sup>
- Youth cancer survivors have a 1.9 times increased risk of developing a second cancer.<sup>v</sup>

*"While cancer in young Australians is rare, it has a substantial social and economic impact on individuals, families and the community".<sup>vi</sup>*

Through Sony Foundation's 'You Can' initiatives, gaps in youth cancer care are being filled by the Foundation funding to build age-appropriate and specialised youth cancer centres and services, tailored to the needs of this unique aiming to improve health and well-being outcomes and reduce barriers to equitable healthcare.

Too old for children's hospitals, and too young to be alongside the elderly during their treatment, the number one need identified by the Senate Inquiry was age-appropriate spaces and services in the hospital. Sony Foundation committed to funding the build of age-appropriate youth cancer centres, 'You Can Centres', within adult hospitals across Australia.

You Can Centres act as hubs for specialised treatment and wrap-around allied health services, as well as social havens away from the hospital wards allowing for youth cancer patients to build peer support networks/friendships. Sony Foundation's



national network of 'You Can Centres', includes the following five sites in New South Wales, Queensland, Victoria and Western Australia, thanks to an investment of \$8,400,000 from Sony Foundation, and additional funding support from the Australian Federal Government (\$1,200,000) and State Governments (\$1,200,000).

In June 2020, Sony Foundation expanded our You Can initiative and launched '**You Can Stay**' to provide essential accommodation to regional and rural youth cancer patients and their families. This program is an innovative accommodation scheme in partnership with Quest Apartment Hotels.

You Can Stay aims to improve: 1) Equitable access to healthcare and increased adherence to treatment regimens; 2) Mental health and well-being of youth cancer patients, and their families; combating the alarming findings:

- 1/3 of Australian cancer patients are from regional or rural areas (does not include patients from inner regional areas);
- Living more than 200 km from an appropriate treating hospital can reduce a patient's chance of surviving a cancer diagnosis by 30%;<sup>vii</sup>
- The financial and emotional cost of travelling for treatment can be a barrier for some patients accessing the best cancer care available in the city.
- There is a lack of appropriate, available, and affordable accommodation for cancer patients in metro cities.
- Adolescents and young adults (AYA) are often diagnosed with rare cancers (e.g. blood, bone and brain) requiring complex treatment plans in specialist city hospitals.
- AYA cancer diagnoses have a significant impact on the broader family:
  - 80% of families report facing financial difficulty in accessing treatment;
  - 1 in 3 carers' capacity for full-time work is reduced, with 12% of parents/carers becoming unemployed;
  - Parents and siblings are separated for extended periods.

Cancer Australia's 'Australian Cancer Plan' published on 2 November 2023, stated:

*"People living in remote areas of Australia are 1.3 times more likely to die from cancer and have a lower 5-year relative survival rate compared to those living in major cities. Additionally, people living in rural and remote areas have higher rates of hospitalisation, death, and injury, and have poorer access to and use of primary health care services than people living in major cities*

*Travel is a significant barrier to accessing health services and can lead to reduced access to cancer care across the care pathway. Additional costs associated with travel to metropolitan centres increases the impact of a cancer diagnosis on a person and their families."*

You Can Stay provides access to a self-contained one/two-bedroom apartment, enabling regional and rural youth cancer patients to stay with their families, near their treating hospital. The accommodation is uncapped and provided at no cost to the patient. You Can Stay accommodation eligibility extends beyond the Government Patient Assisted Travel Subsidy supporting outer-metropolitan and clinical trial patients, and those requiring interstate relocation. Sony Foundation covers all costs of the accommodation.

Since June 2020, You Can Stay has supported 300+ patients nationally aged 15-25 years with nearly 20,000 nights of free accommodation. Sony Foundation has provided approximately \$3,300,000 in funding, with no out-of-pocket expenses to families of patients. From November 2023, Sony Foundation will extend the eligibility of You Can Stay to support patients aged 15-29 years, which will see the program double. To date, the average stay for a patient, and their family, equates to 60 nights (two months), with stays up to 18 months; with some patients requiring multiple stays. *Please see some case studies from You Can Stay beneficiaries, and recent referrals in Appendix 1.*

The impact of You Can Stay was illustrated in Sony Foundation's 2021 report 'Counting the Cost of Accommodating Cancer: Regional Families of Youth with Cancer Reflect on a Road Less Travelled' prepared by Professor Susan Sawyer, Ms Ella Cehun and Ms Catherine Waters; Centre for Adolescent Health, Murdoch Children's Research Institute and Royal Children's Hospital and Department of Paediatrics, The University of Melbourne. The report highlighted the issues impacting regional families with a youth diagnosed with cancer who had to travel to the city for cancer treatment:



- 80% faced financial difficulty due to cancer diagnosis; with 33% of carers' capacity for full-time work reduced, and 12% of carers becoming unemployed.
- 60% of families/carers would not have been able to accompany their child or have their immediate family stay if accommodation wasn't provided.
- 18% of patients were not eligible for a government rebate/subsidy.

Outside of the cancer space, youth are surviving non-communicable diseases at higher rates but are often left living with chronic illnesses that significantly impact the patient's health and well-being.

Non-communicable diseases and chronic illnesses generally require multi-disciplinary healthcare teams to address the complex needs of patients. For regional and rural patients, this becomes a health equity issue as they are not able to access these specialists in regional hospitals; and like youth cancer patients, face disproportionate financial and psychosocial burdens in accessing healthcare and support services.

The Youth Cancer accommodation model of bridging a gap by providing essential age-appropriate funded accommodation is proving to be a best-in-class model for addressing the significant burden on regional and rural patients and their families who have to travel to cities for treatment.

As such, Sony Foundation is collaborating with other charitable organisations and private/institutional developers, to create a mutually beneficial solution to the accommodation crisis for regional and rural patients building on the model of, and key learnings from, You Can Stay. Creating a sector-wide approach, Sony Foundation aims for this solution to provide essential support for regional and rural youth patients, and the possibility of expansion of this support to other age cohorts.

For Sony Foundation to invest in the build of accommodation apartments and to fund the operation, is cost prohibitive. As such, Sony Foundation is reliant upon adapting the innovative models of affordable and social housing and build to rent, developed in the Australian housing sector; through the establishment of private-public partnerships to combat an alarming health and well-being equity issue.

**The proposed solution involves an adaption of affordable and social housing models, in collaboration with the Government (providing access to land), Sony Foundation (providing funding), in partnership with a developer (providing a proportion of the apartments to the Foundation and its charitable partners). Sony Foundation will then manage the operation of the 'donated' apartments in collaboration with NGO health sector partners to provide essential short-term accommodation to regional and rural patients and their families.**

Sony Foundation has been delivering the You Can Stay program for the past three years and has created a cost-effective and hugely impactful program. We believe that this support could be expanded based on the above model to provide effective, cost-efficient, sustainable assistance to Australian youth with severe illness.

Sony Foundation appreciates Housing Australia's and The Treasury's commitment to supporting the development of more social and affordable homes across Australia, encouraging greater private and institutional development into this social issue. **Sony Foundation is grateful for Housing Australia's and The Treasury's consideration of expanding the focus beneficiary demographics within the *Housing Australia Investment Mandate Amendment (Social Housing, Affordable Housing and Acute Housing Needs) Direction 2023*, to include youth, with a focus on the acute housing/accommodation needs of youth with disability. Sony Foundation estimates the cohort that could be supported by the expansion of this eligibility to be 45,000+ youth, and their families/carers.**

Sony Foundation defines:

- Youth: individuals aged 15-25 years; as provided by the Australian Charities and Not-for-profits Commission;
- Disability: to include chronic diseases.
  - Sony Foundation follows The Disability Discrimination Act 1992 (Cth):

- "disability" , in relation to a person, means:
  - (a) total or partial loss of the person's bodily or mental functions; or
  - (b) total or partial loss of a part of the body; or
  - (c) the presence in the body of organisms causing disease or illness; or
  - (d) the presence in the body of organisms capable of causing disease or illness; or
  - (e) the malfunction, malformation or disfigurement of a part of the person's body; or
  - (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
  - (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

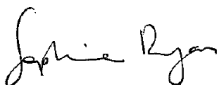
- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future (including because of a genetic predisposition to that disability); or
- (k) is imputed to a person.

Sony Foundation remains committed to supporting the health and well-being outcomes of Australian youth, by reducing inequitable access to services and spaces, including affordable, appropriate and safe accommodation.

Sony Foundation is hopeful to have Housing Australia's and The Treasury's support of this mission, through the expansion of the funding mechanism to support youth, and the acute housing/accommodation needs of youth, notably, **youth with disability**.

Thank you in advance for your consideration. Sony Foundation welcomes the opportunity to meet, to share insights and learnings.

In gratitude,



Sophie Ryan  
CEO, Sony Foundation Australia  
M: 0432 078 426  
[sophie@sonyfoundation.org.au](mailto:sophie@sonyfoundation.org.au)

#### **APPENDIX 1:**

##### **Recent referrals:**

**Name:** B

**Age:** 17

**Diagnosis:** Relapsed Osteosarcoma

**Check in date:** 16 November 2023 | **Expected check out date:** 16 January 2024

**Distance to treating hospital from home:** 901 km

**Referral overview:** *B is a 17 yo male with relapsed disease. He has previously had treatment at HOSPITAL but is now transitioning to HOSPITAL for continued care. He lives in TOWN which is about 9 hours away from Brisbane. He will be travelling with his mother and grandmother. The family would benefit from staying nearby to the HOSPITAL as this will assist with easy access to the hospital for his appointments and treatment. I have only talked with Nicole over the phone and will meet them in person at their first appointment. The family are understandably overwhelmed with this relapsed disease and impact on Blake and family. They are a rural family. At this stage I have requested a 2 month stay however will know more once the family arrive and initial appointments and treatment commence.*

**Name:** D

**Diagnosis:** Osteosarcoma

**Check in date:** 12 November 2023 | **Expected check out date:** 15 November 2024

**Distance to treating hospital from home:** 216 km

**Reason for stay:** *D is from S and travels to Brisbane for his treatment. He has osteosarcoma and is still on active treatment. He has a limited income and would be unable to afford to pay for accommodation in Brisbane without this support. He has treatment next week which has been delayed given his blood results. The support you provide Dylan is appreciated.*

**Beneficiary feedback:**

**TAHLIA, QLD**

**Age:** 18 | **Distance from home:** 125+ km | **Nights away from home:** 30+

*"Sony Foundation were there for my family when we needed them the most. I'd already spent time in hospital, my parents had exhausted their savings, used up their sick leave and would have been left with no other choice but endure financial hardship to stay close to the hospital and be by my side during treatment. With the You Can Stay program, our family was free of the extra monetary stress, and we were able to be together."*

**JACK, QLD**

**Age:** 21 | **Distance from home:** 215+ km | **Nights away from home:** 40+

*"If it wasn't for the Sony Foundation helping us out with our accommodation we probably wouldn't have been able to have stayed as close to the hospital and would have done a lot more driving, which would have taken a bigger toll on myself physically. The peace of mind that came with knowing we would be able to call up and have a place to stay in Brisbane took a huge weight off my family's shoulders, and made life a lot less stressful for my parents in particular"*

**ANNABEL, ACT**

**Age:** 17 | **Distance from home:** 290+ km | **Nights away from home:** 480+

*"Our apartment became our home away from home. I had space for my artwork. I had the privacy to cry and scream when things got too painful and overwhelmed me. Mum was able to provide home cooked meals. We could also be a family when my Dad and Sister were able to visit."*

**HARRIET, SA**

**Age:** 17 | **Distance from home:** 1,322+ km | **Nights away from home:** 90+

*"When I was 15, I was diagnosed with Ewing's Sarcoma in my hip, pelvis and bladder region at the start of 2020, and the COVID-19 pandemic. I was required to travel to Sydney for my surgery and was in hospital over there for over two long, hard months. It was so emotionally and physically difficult for myself and my family. Without the You Can Stay program, my parents and sister would not have been able to be there for me in Sydney long-term and I would have been left mostly alone!"*

---

<sup>i</sup> Australian Institute of Health and Welfare. (2023). *Cancer in adolescents and young adults in Australia 2023*. Canberra: AIHW.

<sup>ii</sup> Bleyer A (2009) 'Adolescent and young adult (AYA) cancers: distinct biology, different therapy?', *Cancer Forum*, 33(1):4–10; Tricoli JV, Seibel NL, Blair DG, Albritton K and Hayes-Lattin B (2011) 'Unique characteristics of adolescent and young adult acute lymphoblastic leukemia, breast cancer, and colon cancer', *Journal of the National Cancer Institute*, 103(8):628–35. doi:10.1093/jnci/djr094; Australian Institute of Health and Welfare. (2023). *Cancer in adolescents and young adults in Australia 2023*. Canberra: AIHW.

<sup>iii</sup> Peter MacCallum Cancer Centre (n.d.) About ONTrac at Peter Mac, Peter MacCallum Cancer Centre website. <https://www.petermac.org/ontrac/about-us>; Australian Institute of Health and Welfare. (2023). *Cancer in adolescents and young adults in Australia 2023*. Canberra: AIHW.

<sup>iv</sup> Seitz DCM, et al. (2010) Post traumatic stress, depression and anxiety among adult long-term survivors of cancer in adolescence. *Eur J Cancer*, 46:1596–1606.

<sup>v</sup> Australian Institute of Health and Welfare. (2023). *Cancer in adolescents and young adults in Australia 2023*. Canberra: AIHW.

<sup>vi</sup> Australian Institute of Health and Welfare. (2023). *Cancer in adolescents and young adults in Australia 2023*. Canberra: AIHW.

<sup>vii</sup> Evohealth, Beardmore et al. (2022). *Shining a light: Radiotherapy cancer Treatment in Australia*.