

Inquiry into the equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

Hobart Hearing –20 February 2024

Additional information

Glen, Private Capacity

1. Our experience of support throughout cancer treatment in the Japanese hospital system is non-discriminatory and regardless of which cancer you're up against, common or rare, the same staff (CNC nurses) provide the same type and level of support. Such support provides enormous practical and psychological benefits to us the patients and probably also in terms of efficient utilisation of resources. Conversely our experiences here in Australia are starkly different with some cancers well-supported by a CNC nurse, other less common and rare cancers not at all with the patient often left flailing in the system.

2. Psychological support has ranged from inadequate to non-existent for us. Often despite our cancers, we're physically well on a day-to-day basis but what happens in the mind takes a terrible toll, such that sometimes it also impacts on our physical well-being. Masumi has been able to access psychology services through RHH but always after a long waiting period and far from frequent enough. With myself post-surgery having been cast aside into the outpatients system, I have found it impossible to access any such services at all - even immediately before, during and after my nephrectomy surgery and without a CNC nurse to advocate for me, the doctors I asked about psychological services knew nothing about how to access or refer.

In the face of such uneven and/or lack of above mentioned support, especially for those with less common cancers, we would like to acknowledge the wonderful support of the staff and volunteers at Cancer Council (TAS) who have been invaluable helped pull us through at times.