



National Travel Assistance (NTA) Scheme

Our call for an update on when urgent improvements will occur to the NTA Scheme

PRESENTED BY:

The AYA Cancer Consumer
Advisory Group

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5th December 2023

Tēnā koe e Dr. Shane Reti

We are the Adolescent and Young Adult (AYA) Consumer Advisory Group, a part of the AYA Cancer Network Aotearoa. Our group consists of 20 young individuals between the ages of 17 and 29 who have all personally experienced cancer during their adolescent and young adult years. We collaborate closely with the Network on significant projects to improve access to treatment and care pathways for young people. Our main goal is to overcome barriers and gaps in cancer care, ultimately leading to better survival and quality of life outcomes. We are passionate advocates for improving cancer treatment and care for young individuals like ourselves in Aotearoa.

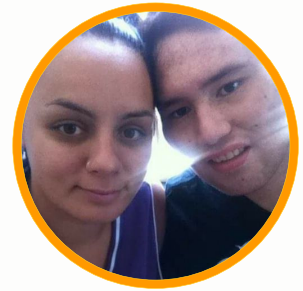
We are writing to request an immediate update on when changes will occur to the National Travel Assistance (NTA) Scheme. Our members feel that previous reviews have not resulted in any meaningful action, which has left many young cancer patients throughout Aotearoa struggling with the burden of travel-related barriers, such as financial stress and difficulty accessing treatment. While the current NTA Scheme is designed to provide financial aid to those with the greatest need, our members believe that there are numerous challenges with the criteria and claims process, making it difficult for those who need support the most to access it.

We have specific examples of how the guidelines have not supported young people and, therefore, increasing inequities. We also suggest how the NTA guidelines can be revised to better serve those we represent. We look forward to hearing back from you and to working with you to find actionable solutions.



A CALL FOR ACTION

“ There are so many barriers that existed for us as low income earners. It was hard, I basically had to beg the system to get what was actually there unbeknown to me. ”
-Justin (right), AYA



Treatment is never a one-and-done situation for young people diagnosed with cancer. For most it will be months – and for some it will be years – spent travelling between home and hospital for cancer treatment, tests, and specialist appointments. On top of being sick, young people have to cover the costs of accommodation and transport upfront and keep track of receipts and forms to provide physical evidence for reimbursement for NTA, some of the funds of which they don't get back. Many young people with cancer do not meet the NTA eligibility criteria and worry about whether they can afford to attend a medical appointment. No one should be faced with deciding whether the cost of travel to get life-saving treatment is more important than eating or paying their bills. Our young people and their whānau are suffering.

The most common issues with NTA reported by our AYA cancer patients include the following:

1. LACK OF AWARENESS OF THE SCHEME



“ I only knew about the NTA scheme through my mum because she was a nurse. However, I found not many others knew about it when I talked to other young cancer patients. Some of them were really bummed they didn't know sooner. It was a shame I was the one first to inform them. ”
-Mike, AYA

Some young people have stated after finishing treatment that they were completely unaware of the NTA scheme and had to fund their own transport and accommodation at the time. They therefore missed out on what they were entitled to and would have been beneficial financial assistance for travel-related costs.

“ I had to go to Dunedin from Christchurch four times for surgery. I didn't even know you could claim it back. ”
-Megan, AYA



ACTION

There needs to be improved communication by healthcare providers about what young people are eligible for under the NTA scheme. Clear processes must be developed nationally to ensure that the NTA scheme is consistently covered in initial treatment discussions with patients, ensuring widespread awareness of available financial travel assistance options.

2. DISCREPANCY BETWEEN ADULT AND CHILD FUNDING

“ It’s hard for us as young people because we often fall into a no man’s land between children and adults. So when it comes to the NTA guidelines, 350 kilometres for adults compared to 80 kilometres for children is a massive difference, especially in how it can affect young people. If you were comparing a 16-year-old to an 18-year-old, who both have a cancer diagnosis and were still financially, emotionally and physically dependent on their family because of it, that is an unfair difference of travel requirement for the 18-year-old compared to the 16-year-old. ”
– Alex, AYA



Currently, young people with cancer who are classified as an ‘adult’ will only be covered under the NTA scheme if they are travelling further than 350 kilometres for medical appointments compared to only 80 kilometres for children. The substantial contrast in eligibility is of great concern. Just like children, young people at 18 and over are often financially, emotionally and physically dependent on their parents or caregivers, especially with a cancer diagnosis.

Nausea is a common side effect for cancer patients. Therefore we feel there needs to be more than just the one option of travelling by car for up to 350kms. A 30-minute flight could be much easier than a 5-hour long drive.

There are also situations where some young people with cancer are classified as ‘adults’ and have their own children who need/want to travel with them. This was the experience for Justin and Chloe from our Consumer Advisory Group. In such cases, there are multiple people travelling, both children and adults, but the NTA criteria is based solely on who is sick.



“ My family went back and forth to hospital every day which was a 50 kilometre round trip per day, which equals 350 kilometres over a week. ”
– Teri, AYA

ACTION

350 kilometres by car is such a long way for a child or young person to travel as an ‘adult’. We believe that distances like 350 kilometres shouldn’t be set in stone. There needs to be flexibility in NTA for individual and family circumstances.

Consideration should also be given to expanding to total travel within a specific timeframe rather than one single trip at 350 kilometres.

3. FUNDING SHORTFALLS

“ Well, the allowance we got for our accommodation didn't even cover half of it. Especially in Auckland, the minimum cost for a room is around \$180 NZD. It was hard to fork out that much money, and it's not like it was a nice getaway holiday too. ”

-Kate, AYA

Currently, the maximum contribution towards accommodation costs is \$100, which is grossly inadequate and does not consider the rapid rise of inflation over the past few years. Finding accommodation for less than \$100 per night across New Zealand is very rare, unless it is a hostel, but that is not a safe or practical environment for a young cancer patient.

Additionally, the reimbursement for petrol is still lower than the actual cost per litre of filling up a vehicle and urgently needs updating. It is also questionable why ACC reimburse people driving in a private car 29 cents per km while the NTA scheme only reimburses 20 cents per kilometre for private transport.

ACTION

We believe the current allowance that only covers up to \$100 for accommodation urgently needs to be increased. The rise of inflation needs to be taken into account as well as other costs such as food and parking which can cost up to \$50 a day, especially in Auckland and other treatment centres.

We also recommend appointing National Travel Assistance (NTA) coordinators at each hospital to address this issue. These coordinators can help facilitate the provision of necessary financial aid for travel-related expenses to access treatment. The role would be similar to existing in-house corporate travel booking systems, which include accommodation, flights, and transportation arrangements. We propose a streamlined booking system that enables health practitioners to arrange patient accommodation and support individuals or whānau efficiently. This would help alleviate the added pressure on patients and their support networks to secure accommodation themselves, and it would promote transparent allocation of funds and beneficial relationships with local accommodation providers.

Additionally, we are advocating for a review of the discrepancy between ACC's higher reimbursement rate of 29 cents per kilometre for petrol costs compared to NTA's rate of 20 cents per kilometre for private transport.

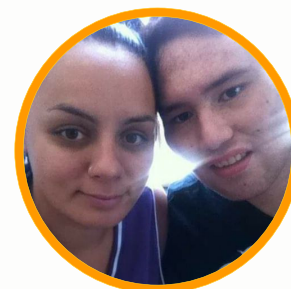
4. WHĀNAU MATTER – A LACK OF FUNDING FOR SUPPORT PEOPLE

“ Due to moving throughout my treatment, I went from feeling supported by one DHB to having another provide less funding under NTA. In my treatment within the Nelson DHB, I required a support person to drive, given I had chemical poisoning to my legs. Unfortunately, unlike the West Coast DHB, the Nelson DHB did not provide funding for a support person. Living 150kms away from the hospital made getting to treatment and specialist appointments really hard. ”
-Chloe, AYA



In Aotearoa, there are disparities in the funding provided for support people such as partners or whānau to accompany AYA to appointments or treatments. At the AYA Cancer Network Aotearoa, we emphasise the importance of having whānau support and believe that no young person should have to go through it alone. We advocate for standard practice across Aotearoa for allowing a support person/s for patients.

“ My whānau were too broke to visit me, and my wife and I never got to see our kids. She worked hard to make \$300 to \$400 a week while my sister watched the kids. Being in the hospital left me feeling lonely, and by myself, I would even hold off coming in when I knew I should as I really didn't want to stay there alone. ”
-Justin, AYA



“ I was staying in CHOC at the time of my treatment, and my family would want to be with me the whole day, every day, so you can imagine how much money in parking that added up to over time. ”
- Teri, AYA

ACTION

NTA is not just about assisting young people in travelling to and from their treatments, but also ensuring that their support people are provided with the necessary support. Therefore, a broader perspective is required to address the needs of both the young person and their support system. Often, patients are limited to a single support person, leading to disruptions within family units. Considering the practical and cultural aspects of patient care, a broader definition of supporting individuals is essential.

The NTA Scheme should cover all costs associated with treatment, including parking, meals, groceries, etc., as these are all additional costs that can add up to a lot for a patient and their whānau/caregivers.

5. NO FLEXIBILITY TO SUPPORT UNIQUE CASES

“ I wasn't eligible for NTA. I seriously financially struggled to get to treatment, and I live in Auckland. I had to either take public transport or walk. I didn't have whānau support either. So, at times when I had no one to pick me up upon discharge, I was forced to order a taxi even though I couldn't afford it because I couldn't take public transport or walk after being on sedatives. It was hard. ”
-Amur, AYA



Patients living in major cities who do not have support people to drive to or from appointments are currently incurring costs for public transport, taxis or parking, further disadvantaging them and adding to their stress. They are not considered under the scheme.

There are some young adults who were told not to drive themselves during treatment but had no other choice at times but to drive themselves because they couldn't access NTA. It is not just a case of saying "don't drive yourself," but also asking further questions such as "do you have other sources of transport you can use?" "Is there someone who can drive you?" and if not then putting supports in place to help young people find transport assistance.

Regardless of distance to treatment, those who do not have access to transport or support networks should be able to access financial assistance, but this is not currently being assessed. For example, someone living merely 15 kilometres from a hospital might not meet the standard criteria. However, if they lack access to a vehicle or support network, are financially incapable of affording public transportation, and experience extreme fatigue due to their treatment, such cases should be acknowledged.

ACTION

The NTA scheme increases inequity. The challenges listed contribute to a more significant divide between patients who can afford to cover the costs of travel and accommodation and those who cannot, further disadvantaging and adding stress to those already experiencing marginalisation and exclusion.

We believe NTA needs to allow for consideration for other factors that play a massive role in an AYAs ability to travel to treatment rather than just on distance alone.

6. INCONVENIENT PROCESSES

“ I didn't really know what was on offer, and I didn't know how hard it was going to be to claim everything. And I had to go for an appointment at the hospital initially once a week, which was a 120km round trip. ”
-Jayden, AYA



Current NTA funding allows those over 18 years old who fall short of the 350-kilometre criteria permission to receive travel assistance if they visit a specialist 22 times within two months. However, the current system requires patients to fill out a form throughout their visits and have each visit signed and dated.

“ I was in the 'can't be bothered' basket. Was too complicated what you had to do for little return. ”
-Jayden, AYA

The processes are difficult for young people to navigate, especially when they are feeling the effects of their cancer treatment.



“ The process of submitting your travel forms to NTA is so ridiculous and outdated. I feel that we shouldn't have to get signatures from our doctors when we've already got chemo brain and are forgetting. ”
Mikyla, AYA

Posting physical copies or receipts or accessing a scanner is limiting, making it difficult for people to claim in a timely manner. Physical receipts also fade and are not always practical. There needs to be a more modern and convenient way to make a claim.

ACTION

We propose creating a system that uses initiatives like RealMe to allow medical staff to sign/ email receipts through an online platform. Paper-based options should remain available as not all people have access to technology. However, a more streamlined approach, such as accepting photo evidence of receipts, can improve the system's convenience for patients and can help speed up the reimbursement process.

7. REIMBURSEMENT MECHANISMS REQUIRE UPFRONT PAYMENT

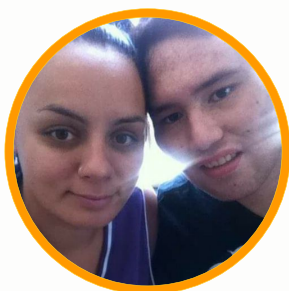
AYA patients and their whānau are challenged with accessing reimbursement under the NTA as they must have the money upfront to pay for petrol/accommodation **before** claiming.

“ Then we have to chase them up, we have to go to the post office, send it away and then wait for 3-4 weeks before that money comes into our account. For a lot of us, we can't afford to wait for hundreds of dollars to come in and we can't pay that money upfront. ”

-Mikyla, AYA



Many do not have have the money to cover the costs upfront or wait to be reimbursed, which can become a significant barrier.



“ I was relying on charities to donate petrol vouchers to get me to appointments. Some weeks, I struggled in order to get help with food to get me and my family through. It was pretty crazy. ”

-Justin, AYA

“ I was given NTA vouchers upfront. So if they're available, why is not a lot of other people getting them? ”

-Alex, AYA



ACTION

The NTA Scheme must recognise that paying upfront and waiting to be reimbursed is not an option for some young people and their whānau. We recommend that if a GP or hospital can confirm a predetermined frequency of medical visits over a specified period, then NTA should allow them to calculate the costs based on travel distance and provide upfront funding via petrol vouchers. And if individuals exceed additional expenses, they should be able to provide supporting evidence for reimbursement to cover these. Income supports from WINZ aren't usually based off of a reimbursement model, why should this be any different?

SUMMARY

in conclusion, the current NTA scheme is insufficient and needs improvement. We recommend immediate adjustments to the allowance for petrol and accommodation to account for inflation and the inclusion of support people in the budget. Additionally, we propose implementing a needs assessment tool to ensure that patients' diverse circumstances and needs are recognised. To help reach more people and streamline processes, we also propose establishing a coordinated communication system involving NTA coordinators in every hospital. Lastly, we recommend simplifying the NTA process and setting up a payment system that enables patients to be paid in advance instead of using the reimbursement mechanism.

With these recommended changes, the revised NTA framework can better adapt and fully address the various circumstances, challenges, and needs of patients who need travel assistance for treatment.

We look forward to your response outlining the proactive steps to address these critical issues.

Nāku iti nei, nā

Adolescent and Young Adult (AYA) Consumer Advisory Group



Ngā mihi maioha



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