



The added cost of growing older: financial impacts of health conditions for over 65s



**TE ARA
AHUNGA ORA**
Retirement Commission

Te Kāwanatanga o Aotearoa
New Zealand Government

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**The added cost of growing older:
financial impacts of health conditions for over 65s**

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Executive summary

As part of its ongoing research programme looking into retirement income, Te Ara Ahunga Ora Retirement Commission has gathered insights on the financial impact of acquiring a disability and/or long-term health condition after the age of 65.

Te Ara Ahunga Ora conducted n=15 interviews with older people who were experiencing at least moderately greater difficulty with a physical condition since turning 65.

Case studies explored specific expenses related to their condition as well as any financial support the participant was able to access.

Key findings include:

- Life shocks mean participants aren't always in the 'financial-shape' they expected. Some people are 'asset rich but cash poor', while others don't have any significant assets to draw on. Inflation and (up until recently) poorly performing investments mean money must stretch further than it used to.
- Health insurance tends to be an early casualty when controlling spending, at a time when it is needed most.
- Degenerative conditions are common among participants and often result in an insidious decline in quality of life.
- Sudden or unexpected conditions / accidents have placed additional physical, emotional and financial burdens on several of the participants. While ACC does cover accidents, several participants reported ACC declined ongoing treatment due to the assumption of 'wear and tear'.
- The lack of health insurance, combined with the potential for ACC to decline ongoing treatment for older people, plus the cost of private care sitting in the 'many-thousands' means participants are reliant on a public health system that is, in many cases, unable to assist within a timely manner.
- Ongoing expenses could be categorised as 'small but regular' (e.g. GPs, scripts, prescriptions¹) and 'expensive but occasional' (e.g. specialists, assistive devices). Both are responsible for erosion of nest eggs.
- Difficulty with, or inability to continue, working (for those that want to do so) is an indirect financial cost that impacts on a disabled individual's ability to recoup costs of treatment.
- The disability allowance contributes to improved quality of life for those receiving it. However, barriers to accessing it include lack of awareness about the allowance, unfamiliarity with WINZ/ MSD, pride in being self-sufficient, shame in feeling incapable, feeling nervous about going into Work and Income, and lack of proactivity by GPs/health professionals.
- Similarly, assistance from Te Whatu Ora and/or Whaikaha is gratefully received, but not everyone is aware of what assistance they can get unless informed by their GP/medical professional (who may not think to offer this support).
- Although there is government assistance for glasses and dental, assets limits mean only the very few can access these. Hearing aid subsidies may be sufficient to contribute to basic hearing aids but fall well short of prices our participants quoted.

¹ As of 1 July 2023, the Government removed \$5 prescription charges.



Recommendations for consideration include:

1. Provision of information as part of retirement planning

Becoming disabled in some way as one ages is a natural part of human experience and should be planned for. Encouraging people to think about the likely health scenarios they may face in their older years is important and could consider:

- Identify and share statistics related to likely disabilities/long-term health conditions that occur in older years such as vision, hearing, and mobility limitations
- Planning for provision for doctors/specialist fees etc, but also unexpected larger health costs particularly for glasses, hearing aids and dental (which are not covered by insurance) and surgery for osteoarthritis or other degenerative conditions (which are not covered by ACC).
- Education on how to effectively and affordably insure one's health (e.g. increasing excess to reduce premiums)
- Health insurance vs self-insurance vs willingness to rely on New Zealand's public health system

2. Asset limits and subsidies/grants

Is the financial assistance available, and the asset limits appropriate given the increases in cost for vision, hearing and dental treatment?

- The asset limits for receiving help with glasses, or immediate or essential dental treatment, is low. Those with only slightly more money believe they would essentially deplete their entire savings with one treatment.
- Assistance for glasses is available but needs to be paid back. Those who are unable to return to work would struggle to recoup and repay the cost for these and could be more arduous for those unable to access the preferred supplier rate (moving from \$280 to \$1,000+).
- At \$1,022.22 for two hearing aids, the New Zealand Hearing Aid subsidy contributes adequately for basic hearing aids but is far below the cost of hearing aids quoted by our participants (~\$4,000 -8,000+). The Hearing Aid Funding Scheme has stricter requirements but may be available to over 65s under some circumstances.

3. Improving accessibility to disability allowance

The disability allowance makes a significant difference to the quality of life of recipients but there are barriers to accessing.

- Not all superannuitants regularly see their GP/community health provider, or they see different professionals at different times, so discussions about the allowance may not arise. This may particularly be the case for degenerative conditions like osteo-arthritis (the insidious nature means people just put up with it, thinking nothing can be done).
- What other avenues could be used to increase awareness and understanding of the allowance? For instance, information about assistance can and should also come from non-medical sources (e.g. faith communities, interest groups, etc).
- Wider discussions / initiatives that address the stigma around disability and the interaction of ableism/ageism can contribute to reducing barriers related to pride and unwillingness to consider support.
- For some, WINZ is associated with a 'welfare system' that many have not had experience with. Perhaps there could be an education piece to strengthen the links between NZ Super (which is perceived favourably) and the Disability allowance?



Introduction

We wish to understand the financial impact of acquiring a disability and/or long-term health condition after the age of 65, assessing relevant changes in income and expenses. The current project will inform policy makers, financial service providers and disability services.



Background

The role of Te Ara Ahunga Ora Retirement Commission is threefold: to raise public understanding and advise Government on policies that will enhance retirement outcome for New Zealanders; monitor effects of the retirement villages legal framework; and help New Zealanders think long-term to improve their financial outcomes and prepare for retirement.

Every three years, Te Ara Ahunga Ora is tasked by the Minister of Commerce and Consumer Affairs to conduct a Review of Retirement Income Policies (RRIP). The Minister sets the Terms of Reference through officials at the Ministry for Business, Innovation and Employment (MBIE). The Terms of Reference may be informed by input from relevant stakeholder organisations, such as Te Ara Ahunga Ora or Office for Seniors.

Among other recommendations made in the 2022 RRIP, the Retirement Commissioner recognised the need for future reviews to also consider disabled people. Incidence of disability increases with age and as such, the numbers of disabled people will increase as the proportion of the population aged 65+ increases. As of 2017, 59% of all people aged over 65 were considered disabled¹.

A 2021 study by Te Ara Ahunga Ora found that participants with disabilities and/or long-term health conditions had lower participation rates in the workforce, lower incomes, lower homeownership rates and lower KiwiSaver participation than those without such conditions². As a result, disabled people who have been unable to accumulate wealth in their younger years will enter their older years with far less to draw on financially.

Looking at people aged 65+ in general, the 2019 Household Expenditure Survey states that average weekly health expenditure for a couple-only household is \$49.70, and \$24.10 for a single household³. It is likely that health expenditure would be higher in households with an older disabled person (or someone with a long-term health condition) compared to households without, but we are unaware of any current public information detailing these expenses.

In addition, there is currently a dearth of information regarding the financial impact of late onset disabilities and/or long-term health conditions in people aged 65+, who have had the opportunity to accumulate wealth in their younger years. Assessment of financial impact needs to consider both financial support related to the disability and to the disability-specific expenses. There are also tangential areas that could be considered, such as ability to supplement NZ Super with paid work, and the need to outsource activities that might once have been done by the individual (e.g. home maintenance, transport, care for others).



² Disability Issues.pdf (beehive.govt.nz)

³ TAAO_focus-on-disability-and-longterm-health-conditions.pdf (retirement.govt.nz)

⁴ Business-of-Ageing-2021-report.pdf (officeforseniors.govt.nz)



Disability related income / financial assistance

In terms of income for those aged 65 years or older, most people are eligible to receive NZ Super, as long as they meet criteria for time residing in New Zealand⁵. In addition, the SuperGold card can be used by many over 65s to assist with transport and other discounts (including aspects of healthcare like glasses and hearing aids).

People who have a disability or condition that is likely to last at least six months and face regular ongoing costs because of the disability (that aren't fully covered by another agency) are also eligible to receive a disability allowance from MSD, as long as their income is below a certain threshold⁶. The allowance can be up to \$75.10 a week, untaxed. Income limits are adjusted on 1 April each year by the increase in the CPI.

Of the approximately 842,100 people aged 65+ in NZ in 2022⁷, 129,522 people⁸ received the disability allowance (15%). This is low given the number of disabled over 65s that we know exist (59%), and is likely explained by the means-testing of the disability allowance, which looks at household income. However, most people completely reliant on NZ Super would be eligible - research conducted by Te Ara Ahunga Ora in 2022 showed that just over 40% of over 65s lived in households where the income was below \$50,000 p.a.⁹, suggesting there may be people who are eligible but not claiming.

Of interest, one of the components of financial wellbeing reported in the 2021 Te Ara Ahunga Ora paper¹⁰ '*resilience for the future*' shows a shrinking gap between those with and without disabilities/long-term health conditions for those aged 65+ compared to the 55-64 year-old group. It is hypothesized that for those who were on very low incomes (e.g. relying on a benefit/allowance) prior to 65, turning 65 may actually represent an improvement in financial situation, since they may receive both a disability allowance and NZ Super in a regular manner.

There are additional health and disability grants/subsidies that are available subject to either income and/or asset based means testing¹¹. MSD offers 'hardship assistance' which is more tightly targeted than main benefits or disability allowance. If a person is completely reliant on NZ Super, they are likely to be able to access assistance for expensive health services (e.g. dental or glasses) because income/asset limits to get financial support for these are set below the rates at which NZ Super is paid. Specifically, the limits are weekly income before tax of less than \$1,308.60 per week for a couple or \$900.93 for a single; and assets worth less than \$2,131.73 for a couple or \$1279.35 for a single.

In terms of glasses, MSD can provide Recoverable Assistance (must be paid back) of \$280 if sourced through an MSD preferred supplier. Those living in an urban area with a preferred supplier or suppliers must use one of those suppliers to be eligible for assistance from MSD. If a client lives in an area without a preferred supplier, they can choose to travel to a preferred supplier at their own cost or visit a non-preferred supplier in their area. In the latter instance, they are unable to utilise the benefits of the competitive pricing that the preferred supplier arrangement offers, and the guideline amount for optical goods and services is \$1,000. Where a client has high clinical needs that cost more than the standard contract price of \$280 (this would include people 65+ with complex vision issues), hardship assistance can be provided at a higher amount for these situations.

5 Must be a New Zealand citizen, or a permanent resident, or hold a residence class visa; are ordinarily resident in New Zealand, the Cook Islands, Niue or Tokelau when applying; and have lived in New Zealand for a least 10 year since turning 20. The 10 years much include 5 years since turning 50. Residence criteria will change in July 2024, gradually increasing from 10 to 20 years.

6 Income limits apply: e.g weekly income (before tax) of \$786.69 for single, \$1,171.42 for a couple regardless of children

7 National population projections: 2020(base)-2073 | Stats NZ

8 Personal correspondence with MSD, 17th July, 2023

9 TAAO - Retiree-preretiree-report (retirement.govt.nz)

10 TAAO_focus-on-disability-and-longterm-health-conditions.pdf (retirement.govt.nz)

11 Health and disability - Work and Income

Similarly, a Special Needs Grant (doesn't need to be paid back) of up to \$1,000 is provided by MSD for dental treatment. The grants are not recoverable, and the \$1,000 can be exceeded in exceptional circumstances. In the past, the requirement for emergency treatment meant people would have to be in pain before being considered. This has changed meaning people can now access treatment before they get to this stage. Income and cash asset levels for Recoverable Assistance and Special Needs Grants are now adjusted on 1 April each year to reflect average wage growth¹.

Subsidies are available from MSD for hearing aids (the Hearing Aid Subsidy Scheme² which provides \$511.11 for each hearing aid once every six years). The Hearing Aid Funding Scheme has stricter requirements relating to significant multiple disabilities and/or Community Service Cardholder criteria but may be available to over 65s under some circumstances³. In addition, MSD may provide Recoverable Assistance to those who meet the above income and cash asset limits, typically up to \$1,000, but more under some circumstances.

Additionally, there are other non-financial sources of assistance provided to disabled people, notably via Te Whatu Ora (Health New Zealand) and Manatū Hauora (Ministry of Health) as well as Whaikaha (Ministry of Disabled People).

- Government funding of health and disability services (the public health system) provides free inpatient and outpatient public hospital services and a range of support services for people with disabilities in the community as long as they are eligible,⁴ although, typically this only relates to people aged under 65. Nevertheless, as of 2018, those aged 65-79 made up 9.2% of those accessing disability support services⁵.
- The national framework for Home and Community Support Services (HCSS) covers Te Whatu Ora services for people aged 65+ who have an assessed need in response to an interRAI assessment (a comprehensive clinical assessment of a person's function) and meet criteria for funding⁶.
- Whaikaha provides funding for home modification, provided the applicant meets asset and income requirements⁷, but other services are targeted more to people younger than 65.



1 Personal correspondence regarding Special Needs Grants and Recoverable Assistance, MSD, 8th August, 2023

2 Guide to Getting Hearing Aids: Hearing Aid Subsidy Scheme (whaikaha.govt.nz)

3 Guide to Getting Hearing Aids: Hearing Aid Funding Scheme | Ministry of Health NZ

4 your-guide-to-disability-support-services-english.pdf (moh.govt.nz): lives in NZ, is a NZ resident and has a long-term disability not covered by ACC

5 demographic-report-for-client-allocated-ministry-of-health-disability-support_services-2018-update14nov2019.docx (live.com)

6 Also considers ethnicity, so for Pacific peoples and Māori, aged over 55 years, and others aged over 60 years, with age-related disabilities. See National Framework for Home and Community Support Services (HCSS) | Ministry of Health NZ

7 What home modifications we can fund | Whaikaha - Ministry of Disabled People



Disability related expenses

We are unaware of any publicly available current research that explores actual expenses related to disability or long-term health conditions in New Zealand for people aged over 65.

StatsNZ has historic information on disability in New Zealand, from a 2013 survey, which is scheduled to be run again (in a revised form) later in 2023¹⁹. While the survey asked about the use of equipment and technology for each disability, it did not assess the dollar amounts spent on these. Similarly, it collected information on use of various health professionals in the last 12 months, but not the costs of those visits; and whether any modifications to the home had been made, but not how much they were. Transport questions also didn't ask about costs.

A study by Te Ara Ahunga Ora (2021) explored how pre-retired people's medical expenditure expectations compared to self-estimates (more, the same, or less) for those aged over 65+ (although no actual amounts were recorded). The main area where people thought they spent more than expected after reaching 65 was prescription medicine, followed by medical products, appliances & services, outpatient services, and insurance. However, the study did not examine actual amounts spent on specific aspects of health and disability.

To contribute to our understanding of the financial impact of late-onset disability and/or long-term health conditions, the following report examines the disability-related income and expenses of disabled people aged 65+. Data takes the form of 15 case studies of people who acquired their disability after the age of 65.

Methodology

Research approach

The nature of the research involved several sensitive topics (finances and health), as well as potentially vulnerable participants, and as such an approach using a qualitative methodology was deemed most appropriate²⁰. The project used a case-study approach, using 15 in-depth interviews. Participants came from around New Zealand, and were comprised of a mix of gender, age brackets over 65, ethnicity, household situation, homeownership, dependence on NZ Super and type and severity of condition. Interviewing was conducted over May 2023.

- Support people were welcome to attend if invited by the participant.
- Phone or online interviews were offered to participants so that they could remain in their home, removing the need to travel.
- We believe our methodology was in keeping with Kaupapa Māori given the opportunity for open ended kōrero, and the ability of the participant to include whānau if they wished. However, budgeting issues meant that we were not able to visit marae (this was not requested by any Māori participants).
- Data collected by the researcher was confidential and reporting was anonymised.

¹⁹ Disability survey: 2013 | Stats NZ

²⁰ Ethics approval was obtained for this study (AREC23_13).



Recruitment

A specialist market research recruitment agency was engaged for the recruitment. The recruiters have a large panel database of people from all around New Zealand with a wide range of specs, who have opted in to take part in research projects. The screener they used (Appendix 1) was targeted to the below requirements. Potential participants clicked on the screener link and completed the survey to see if they fit for the project. Those that did were personally called by the team of recruiters to talk them through what was involved and then recruited if appropriate. A total of 15 people took part in the project (see table 1 for demographic breakdown).

- Consent forms were completed prior to any sensitive information being collected.

Participants were all aged 65+ and answered at least a 'moderate increase in difficulty' to the question 'Thinking about your life now, which of the following have you experienced increased difficulty with compared to your life prior to 65'. Other qualifying information included the following:

- Must be someone who has experienced a change in their expenditure or income as a direct result of the condition.
- 50:50 split male:female (or close)
- Age: 65-69, 70-74, 75+
- A mix of ethnicities (aiming for 3 x Māori, 1 x Pacific person, 1 x Asian person)
- Range of home tenure (own with mortgage, own without mortgage, renting, living with family)
- Range of living situations: single living alone, single living with others, living with a partner, living with family
- Range of disabilities and conditions (lasting longer than six months):
 - Vision
 - Hearing
 - Mobility /agility
- We did not recruit for those experiencing psychiatric or intellectual conditions (e.g. dementia, memory) where participants would be particularly vulnerable
- Range of severities (in terms of impact on daily activities) but needed at least some impact financially (expenses and/or income). E.g. Buying a hearing aid you weren't expecting to have to do
- Range of sources of income (reliant on NZ Super, KiwiSaver, Other savings/investments)
- Range of location: rural / urban, North Island / South Island



Table 1. Sample profile of participants in the study (n=15)

		N=
Gender	Male	8
	Female	7
Age	65-69	5
	70-74	4
	75+	6
Ethnicity	NZ European	8
	Māori	3
	Asian	3
	Other	1
Living situation	Single	7
	With partner	5
	Multigenerational	1
	Others (e.g. family, boarders)	2
Homeownership	Own, no mortgage	8
	Own, mortgage	2
	Rent	3
	Partner's home	2
Region	Auckland	7
	Wellington	3
	Canterbury	2
	Other	3
Reliance on NZ Super	All of my income	7
	At least two-thirds of my income	5
	At least one-third of my income	3
Disability (can have more than one), av=1.7	Eyesight	8
	Hearing	3
	Osteoarthritis / joints / mobility	9
	Other (falls, heart, cancer etc)	6



Discussion guide

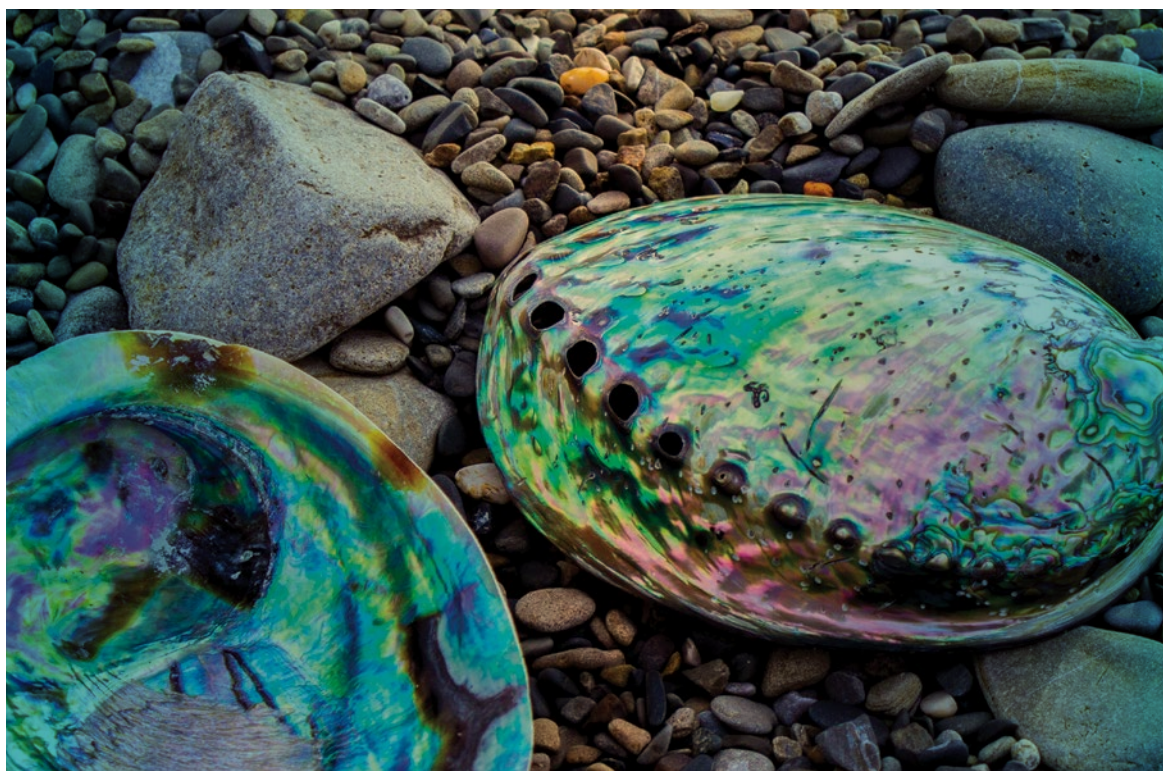
Appendix 2 contains the discussion guide that was followed by the interviewer. Structure was such that rapport was first established, followed by a discussion of what life was like in their 50s, a brief discussion about their current disability(ies), their sources of income (not actual \$ amounts), and expenses related to their disability(ies) (estimated \$ amounts). At completion of the interview, participants were provided with a contact list of relevant counselling, financial and disability assistance providers.

Limitations of the study

The study uses qualitative methods to collect data. As such, the aim is to gain in-depth insight into the lives of some older people who experience long-term conditions that have impacted their lives after turning 65. Although we have attempted to speak with a range of participants from different backgrounds, ethnicities, or financial situation, it does not suggest representation of the population of disabled over-65s. While attempts were made, we were not able to recruit anyone from a Pacific Island ethnicity and this is something that should be pursued in future research.

Some participants were able to recall in more detail (in \$ terms) expenses related to their disability(ies), while others tended to 'ballpark' the figures. The study is also not an exhaustive assessment of exact financial expenses related to disability. Rather we aim to understand the types of expenses and the impacts that they have on the financial wellbeing of our participants.

The definition of 'disability/long-term health condition' in this study is considered to be a physical condition that the participant has experienced at least moderately greater difficulty with since turning 65. Rather than limiting our sample to people who have conditions that are not adequately corrected through the use of devices, we have intentionally kept criteria broad so that we can understand the continuum of expenses. Older people with particularly debilitating conditions are likely to have even greater needs and consequently even higher expenses.



Research findings

Conditions are typically degenerative rather than sudden, appearing in their 60s but accelerating into the 70s.

- Seen as simply 'getting old': just keep putting up with it, even when they get to the stage that they experience ongoing discomfort or pain
- Osteo-arthritis is particularly bad for this, being quite insidious
- Eyesight and hearing also decline gradually until it starts impacting on ability to do things.

On top of degenerative conditions, several of our participants also experienced sudden or unexpected disabilities / long-term health conditions such as heart attacks requiring stents, bone breaks that haven't healed properly, serious eye conditions, strokes, and herniated discs.

Theoretically those who have lived their working life without a disability or long-term health condition would have had a greater opportunity to accumulate wealth and pay off a mortgage, meaning they would have sufficient funds to deal with both degenerative and unexpected disabilities. However, for a number of our participants, life shocks such as divorce, earthquakes, financial mistakes and redundancy have meant they are not in the 'financial-shape' they thought they would be after the age of 65.

- Our results also show that some people have attained mortgage-free status but have very little in the way of cash-wealth (asset rich but cash poor). Disabled homeowners face the double burden of expenses and financial requirements to maintain the value of their asset (although there are additional forms of support from the Government for those on very low incomes)²¹ plus unexpected or ongoing expenses related to health.
- On the flipside are individuals who don't own their home but have nest eggs put aside. While they don't have the responsibility for home maintenance, they also don't have the ability to draw on a significant asset so face the fear of outliving their savings.

In both situations, a major health-related expense can be impossible to consider without health insurance. However, as premiums increase in later life, some people find the cost prohibitive and cancel their health insurance. With no opportunity for paid work to pay off debt, disabled superannuitants must wait their turn in the public health system, in some cases for years which impacts on quality of life.

The role of spouse or family ('natural supports' according to the disability sector) is important because they can help with the gradual adjustment, extending the ability to be independent (see 'Arjan', whose wife helps him with dressing so that he can drive the family to where they need to go; or 'Nancy', who receives financial support from her daughter to attend a pain clinic). However, the strain of caring for a disabled person can contribute to disability for the carer in the long-term, (mentally or physically), and reduce their ability to earn an income. In addition, the belief that the care provided by family negates the need for government support means people may not be getting valuable assistance that helps their entire support network (again, see 'Arjan').

- Those who live on their own are much more likely to experience social isolation and feeling emotionally down.

²¹ Get financial help with housing | New Zealand Government (www.govt.nz)



Disability-related expenses

Disability related expenses appear to fall into the 'small but frequent' and 'expensive but irregular' categories. For some of our participants, those small but regular expenses slowly eat away at nest eggs that are not currently producing income. 'Small' but frequent expenses include GP visits, GP charges for scripts, and prescription fees (although prescription charges have since been removed):

- GP: \$20, as often as once a month but typically every 3-6 months, although cost depends on whether the person is still in paid work (\$50-60 per visit)
- Script charges: \$19
- Prescriptions: \$5-20/month (Chemist Warehouse is free but not always convenient)²²
- Physio / chiropractors / acupuncture / massage: ~\$50-100 per visit (may be subsidised by ACC)
- Support devices (e.g. wrist or knee braces): ~\$40

'Expensive' but irregular expenses are even more concerning to participants since the impact on their nest eggs is more pronounced and are harder to manage via budgeting or saving up. Examples include:

- Glasses: \$1,000+ every 2-4 years as eyesight changes, although this can be reduced to around \$500 by re-using frames. Cheap lenses may not be appropriate given the complexity of vision in older people (e.g. the need for progressive lenses)
- Hearing aids: ~\$7,000 which includes a government subsidy – if lucky, this can be a one-off expense
- Dental: ~\$2,000 for an implant, ~\$1000 for a crown
- Supportive shoes, protective sunglasses: ~\$250-500 depending
- Specialists may be covered if under ACC or the health system, but otherwise are around \$200-300 per visit.

Participants comment on finding ways to cut costs for expensive items or prioritising what they will do. For instance, 'Jason' went on TradeMe to purchase second-hand hearing aids, but still faces an \$800 audiologist bill for reprogramming them. 'Yvonne' tries to reuse her glasses frames for as long as possible each time she needs a new prescription. 'Arnold' has put off his dental work as something that is just 'too expensive'.

On top of the expenses for conditions associated with 'old-age', sudden incidents or an unexpected diagnosis can really throw finances out, causing significant worry. ACC may provide assistance in the case of accidents but some of our participants found it hard to prove their injury wasn't wear and tear.

- Participants report costs in the many thousands (eye surgery: \$3,500 for each eye; \$23,000 for knee surgery, ~\$12,000 for a heart stent).

For those that find any form of health insurance beyond their means, access to public health services like x-rays/other imaging is reportedly fairly prompt (within a matter of weeks), but specialists take more time to see (up to several months). Surgery waiting lists represent the biggest hurdle our participants face in accessing care through the public health system - for some conditions like hip or eye surgery the waitlist is several years long. While people wait their turn for the procedure, their condition slowly gets worse, reducing their quality of life. Those who do opt to go private have had to reprioritise other important things, such as travelling to see family. Some have also had to prioritise which disability to treat.

In contrast, as one of only two participants with health insurance, 'Lisa' has managed the significant expense of health insurance by increasing the excess to \$1,000 and moving to a surgery only policy. It has proven well worth it though as it has enabled \$70,000 worth of surgery for breast cancer, an ankle fusion and two hip replacements.

²² Going forward, prescription fees will not be an expense given the removal of prescription fees.

Financial support

Those who accessed the disability allowance are very appreciative of it and are able to use it to improve their quality of life and lift the burden of maintaining their home.

Additional, non-financial assistance from places like Te Whatu Ora and MSD also make a considerable difference to quality of life (see 'Paul', who was able to get modifications made to his rented home to help with the severe arthritis in his hands and received a subsidy on his car repayments).

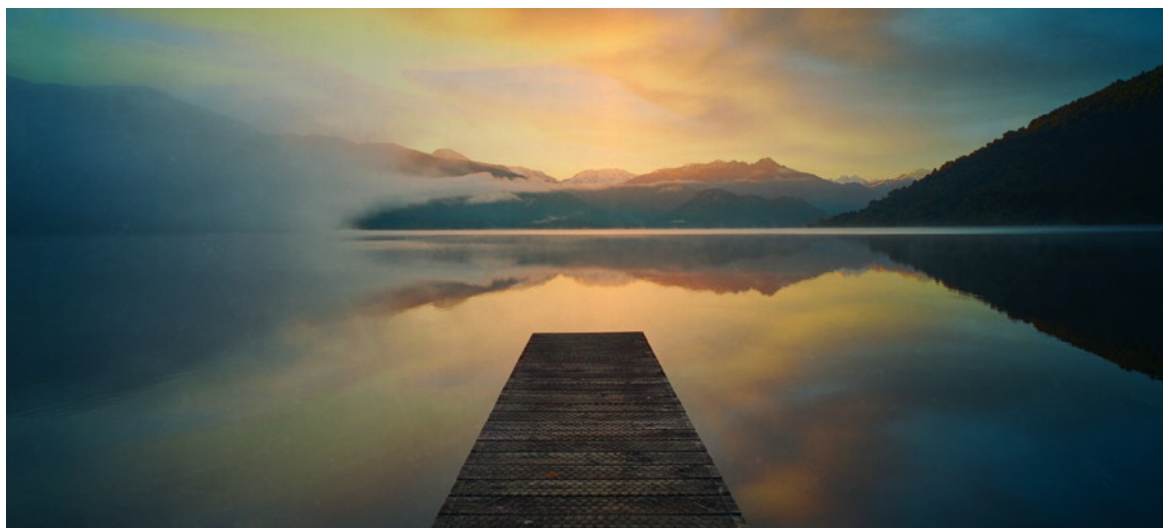
Access to financial support can depend on the proactivity on the GP or public health professional. For instance, they can play a big role in getting assistance with home modifications. They are also important in terms of applying for the disability allowance (for instance, 'Nancy' was able to get her GP to help her apply so that she could have her pain clinic treatment funded).

It will also depend on the proactivity of the superannuitant (for instance, compare 'Arjan' who was unaware of the disability allowance to 'Paul' who utilised MSD extensively for assistance).

For 'third tier' assistance such as Recovery Assistance or Special Needs Grants, cash asset levels are very low (assets worth less than \$2,131.73 for a couple or \$1279.35 for a single) considering the cost of treatment quoted by our participants. Those entirely reliant on NZ Super would meet these requirements from an income perspective but those with only a little more in their nest egg may believe they are ineligible for financial support and may either go without the treatment / items or find themselves without any funds at all after paying for them.

There are other barriers to accessing financial or health support beyond eligibility criteria. These include:

- Fear of going to MSD (e.g it is the same location as for those on other types of benefits, guards on the doors – see 'Trudy')
- Unfamiliarity - for some this would be their first contact with MSD (NZ Super being the exception)
- Pride – they see themselves as successful and independent, they aren't used to asking for help
- Lack of awareness of what they might be eligible for (assumptions being made about assets or working status)
- The belief that their condition is 'just life' and nothing can be done about it
- Lack of proactivity of the GP / medical professional



Case studies





Vincent (Chinese Malaysian, 67)

Living with his partner in a home she owns. Works fulltime, no health insurance

When Vincent was in his 50s he took pride in being extremely active, playing 2-3 sports a week, 4-5 times a week. He enjoyed travelling, often going back to Malaysia to visit family and friends and indulge in the fantastic food. At the time, he lived with his first wife in a home they both owned and was still at the stage of paying a mortgage. He contributed to KiwiSaver from its inception at a rate of 3%. He felt it was a “no brainer because my employer was also contributing”. This was his only form of saving due to also paying the mortgage. Despite this, he feels that he was really living in the present and had little thought for the future.

He eventually separated from his wife and she took ownership of the family home. Eventually Vincent met someone new and currently lives with her in a home that she owns - he contributes significantly to household expenses. His current partner tends to plan ahead more than Vincent and he describes her as a bit more of a worrier. Up until recently, Vincent has continued to be very active playing tennis, badminton and cycling. He continues to work fulltime (working from home a couple of days a week), enjoying the opportunity to socialise with both club mates and work mates. Because he is still working he is able to contribute 10% to his KiwiSaver. He is financially comfortable and NZ Super makes up around a third of his income.

A couple of years ago, Vincent experienced pain in his knee. He discovered that he was developing osteo-arthritis from a sport injury from long ago. The knee eventually locked up. He went to his GP who sent him to a specialist. Unfortunately, the specialist told him that the knee wasn't severe enough to qualify him for the public health waiting system. Without health insurance, Vincent had to just wait it out and opted for a cortisol injection. The knee eventually recovered to some extent but he found he had to reduce some of his sport activities, dropping his beloved badminton. Nevertheless, he still socialises with his old club mates.

However, recently Vincent's knee has become much worse and has locked again. This time it's lasted several weeks and he is again considering going to the specialist. He is intending to ask if his GP can organise some crutches for him in the meantime. Vincent hasn't been able to go into work or participate in any sport, and this is making him feel very down and isolated.

Income:

NZ Super, wages

Expenses related to the disability:

GP visits, Specialist visit, x rays (about \$40); a knee brace (\$50-70); acupuncturist (\$40-50 per visit).

In this situation, Vincent's job enables him to work from home so there has been no impact on his income. However, the lack of health insurance means that Vincent can't go private and has instead seen his condition become progressively worse. He could not afford the '5-digit' cost of surgery to fund it himself. The main cost to Vincent currently takes the form of a toll on his mental health through increasing social isolation.



Arjan (Indian, 73)

Lives in a multigenerational home with a mortgage. Retired due to his disability, no health insurance

In his early 50s, Arjan worked in India, running a real estate company. He enjoyed the opportunity to meet lots of new people. However, in 2002 he and his wife decided to immigrate to another country and chose New Zealand. In the early days he had a desk job, but then set up a shuttle company where he employed a number of drivers, as well as driving himself. After a few iterations of the shuttle company he decided to retire in 2016. He and his wife owned the house he currently lives in, but these days their son has taken over ownership, now paying for the mortgage. This is a big weight off his shoulders.

He did contribute a small amount to KiwiSaver, but when self-employed he stopped contributing. Arjan and his partner found New Zealand much more expensive to live in than expected, and he withdrew his KiwiSaver funds once he became eligible to do so. He has no other form of saving, primarily because he was not earning very much while working, but also because they were using their money to live life in the present. Due to the cost of living, he is finding that their pension no longer covers their everyday expenses: *"Weekly costs have more than doubled, and I have stopped eating eggs. They were \$8 but now \$18! You have to think twice because of your income. Unless you can do a part-time job... I would appreciate more income."*

He does have extended family who can help but at some point he is considering applying for an accommodation supplement for senior citizens.

He's always enjoyed being active, particularly being out in nature and sees himself as a real animal person. He's slowed down over the years, and while still out and about feels he is certainly less 'brisk' in his exercise compared to his younger years. His favourite activity is to go out to a park, go for a walk and do some people

watching. He still drives for the family since the ladies in the house don't drive. This means he's out getting shopping, getting his daughter to work, or picking up the grandkids from school.

Arjan's physical condition has seen a decline over recent years and he now experiences very painful advanced osteo-arthritis in his neck, shoulders, and right lower back. He is able to drive for short periods of time, but driving makes the pain much worse, particularly trying to open the door or apply the handbrake. He is trying to be independent and do things for himself, but he requires his wife to help him, especially when it comes to showering and dressing. He'd love to continue working in some sort of part-time role to supplement his income but needs it to be something that doesn't involve lifting. Ideally it would be something online or via phone, such as customer service. So far he has not had any luck finding such a role.

When queried as to whether he received any disability allowance he didn't know he could apply for it. He acknowledges that there are 'perks from the NZ Government and social system' that can help (e.g. he doesn't have to pay doctor's fees). Indeed, he feels well supported by the health system and he's not had to spend 'much from the pocket'. When he had a blood clot, the MRI was free, and the injections he now requires are also free. It has been suggested he have steroid injections but he's 'not for that' because he doesn't want to make things worse.

Income:

NZ Super

Expenses related to the disability:

None but he's relying on his wife to help him with everyday activities. He's aware that as she gets older, she won't be able to carry out these tasks.

In Arjan's case the cost of his disability is the inability to continue in the workforce to supplement his pension. He does have extended family who can help but at some point he is considering applying for an accommodation supplement for senior citizens. Accessing the disability allowance would help to lift the burden he feels about finding some part-time work.



Arnold (Hispanic, 67)

Lives with his partner in a home she owns. Works full time, has health insurance

Arnold currently works full time in warehouse operations doing everything from 'changing the lightbulbs' to HR, and everything in between. He works fairly long hours at the job. He has been active with rugby league, playing for the local team for the last six years. His biggest hobby is his vintage car, which is his 'baby' (pride and joy) that he takes out in the weekend. He admits it's an expensive hobby particularly because it's a gas guzzler. His job is physical, and he admits that he tries to cover up his ailments so they don't realise that he's in pain. *"My boss has told me as long as your body holds up, you've got a job here. Well, OK. Well, what happens when my body doesn't hold up? You know what? What's gonna happen then?"*

He is also keen on taking up another part time job in the weekends in the travel industry – something he did when he lived in the US for seven years. Overall, he sees himself as enjoying being busy and hates the concept of lying around watching TV.

During his 50s he was married to another woman with whom he had a daughter and son (now 18 and 15) so he was busy being a father to them at this time. *"My 50s were pretty much revolving around my children every other weekend, spending time with them."*

At the time, he and his wife were purchasing the family home together, but they subsequently separated, and the ex-wife got the family home. Physically he was more active than now, and it was at this stage he started playing rugby and league. *"I decided that I was going to make more out of my life getting into my senior years. I wanted to enjoy it as much as possible."*

Income:

NZ Super, wages, KiwiSaver

Expenses related to the disability:

- GP visits: \$40-50 (not covered because he is still working) every 2-3 months
- Physio: \$20 per visit (often needing up to 6 sessions)
- Glasses: \$1,000 (he went for the deal where the optometrist checkup is covered in the glasses)
- Special running shoes: \$268
- Specialist: couldn't remember
- Health insurance: general GP and surgery
- Medication (muscle relaxers): \$5 per 2-3 months
- Painkillers (off shelf)
- Wrist brace: unspecified

However, he wasn't putting much money aside for retirement. He did have a KiwiSaver account he contributed to though. When he turned 66 he used the KiwiSaver to buy his car with the belief that this would be an asset that would appreciate in value given it's 'classic' status. He is still contributing 4% which his employer matches, with the aim of preparing for the future.

Compared to his 50s he is less active in that he doesn't play rugby anymore, mainly because his team thinks he's too old and don't want him to get hurt. He also suspects they may not want to lose. *"Well, other teams have 70 and 75 year olds playing for them, but know what the club that I played for said? 'No, we don't want you on because we don't want you to get hurt', but they're like they're undefeated. So it's more about the winning than it is about not getting hurt."*

He admits he has slowed down and now wears glasses all the time. His body isn't as agile as it used to be.

He's also spending more on health – he's had to get two changes of glasses over the last couple of years, and his hands and ankles are painful. He has calcium buildup in his ankles and has to go downstairs sideways. He also has trouble walking any distance. He's finding the cost of the glasses very expensive and can't afford to go to regular physio. ACC doesn't cover these costs.

"And even with me working full time, I'm still struggling to afford some of these things. But if I wasn't employed, I'm thinking about those people I look over in the waiting room. I'm thinking, hey, you've got to pay that. I know how much you get. And if you're retired, man, that's gonna hurt. That's gonna bite."

Dental is another area of concern for him – he says his teeth are bad but he can't afford the \$2000+ for crowns or implants.

"You're just getting old. They're [the drugs] not working. Ohh I need to take more. And then you're feeling great and you stopped taking them because you forget because you're feeling great. Then all of a sudden you think? Ohh man, I'm not feeling great. Can't do what I used to. As soon as I get on the field, I stretch and I know that I'm gonna be running around and I'll do it. And then I'll pay for it. Pain for two or three days after, cause the adrenaline gets you going. You not realising it. It masks what you're doing."





Annette (Māori, 68)

Lives with a boarder, owns her home with a small mortgage. Retired but wants to work, no health insurance

In her 50s, Annette was working for the council, as well as running a side business at home doing massage. But her home was destroyed in the earthquakes. She eventually got a job working for a Māori trust, doing healing with people who had lost their houses. Following that, she went down south and considered it good timing since she was having many issues getting a settlement for her house. Fortunately, she was insured and got a pay-out from the insurance company which cleared the mortgage on the damaged home. She's been in her current home for 8-9 years. She had health insurance when she was employed by the council but ceased that once she left. At the time, she had no thoughts about retirement, feeling like she was simply in survival mode, trying to get through the earthquake fallout and become established in a new home.

Nowadays, Annette is retired but wants to set up another health business, focusing on helping people with healing. She enjoys going out for coffee with her friends when she can and finds life much easier and relaxed. However, Annette has problems with her knees, is pre-diabetic and has high blood pressure. Her first issue with her knee was a few years ago. She got quoted around \$23k to do the surgery privately, so went on a waiting list for six years before she could get it fixed – this has really improved the quality of her life. Unfortunately, her other knee has now given out, but the waiting list appears to be shorter (2 years) and she has an initial consultation coming up. She has also been told she has a serious condition in her eyes – very upsetting particularly as she has been told that it's important they are done as soon as possible. The waitlist however is very hard to get on to, so she is considering trying to pay for this privately.

Income:

NZ Super, occasional earnings from business

Expenses related to the disability:

- GP visits: \$20 per visit
- Scripts: \$20/per three months
- Pain relief
- Eye surgery: ~\$3.5k per eye
- No transport costs expected (a friend will get her to her appointments)
- No modifications in the home
- Home help is provided by the hospital after knee surgery (although they didn't show up for 3 weeks after her last operation so a neighbour helped her).

Annette wants to reiterate the importance of getting funding through MSD to subsidise eye surgery. *"It's so important for keeping people independent. The scariest thing is the waiting list. Even Māori trusts don't help with the elderly. It should be their primary thing is health care for elderly. And health insurance is too expensive."*





Nancy (NZ European, 77)

Single, lives with her brother in a rented home. Completely retired, no health insurance

Nancy moved from Auckland in her 50s to Wellington, having worked in Auckland at a DHB, managing teams and a home healthcare team. She was renting because although she owned a home in her 40s, she sold that house and put money into doing up houses. Unfortunately, by the time she went back to market she was priced out. Financially she felt she was ok and worked until 68 to keep her finances in reasonably condition. In her last 10 years of working, she made sure she contributed the maximum to her KiwiSaver.

Nancy retired 2014. At the time her brother had trouble finding work, so she supported him for a while, which chewed into the funds. She now lives in a rental home with her brother in Wellington. They share for financial reasons, and she has a daughter who lives fairly close who helps out financially too. Her brother pays rent and she pays for bills. Nancy does some spinning and weaving which she occasionally sells to supplement her income. She is very involved in a creative-fibre group which is important to her mentally and socially since it gets her out of the house. Spinning and weaving has been a lifesaver in terms of making a new social circle when she moved to Wellington.

Income:

- NZ Super
- Disability allowance (\$70/week)
- KiwiSaver has been withdrawn and put into a term deposit – interest is taken from it to pay for things like car expenses, and she then reinvests it.
- A small stipend from her daughter
- Has a mobility card ('the Golden Card')

Expenses related to disability:

- Pain clinic - \$145 per fortnight, paid for by the disability allowance (originally paid for by the daughter)
- Sleep clinic –mandibular splint which is not funded (\$600) related to sleep apnoea
- GP, every 3 months for blood pressure related medications
- X-rays: free
- Transport - \$0: Brother drives and daughter works (from home) so they can help her get to where she needs, but still drives too
- Paracetamol, on prescription
- Glasses: Typically \$1,500 every four years, but they had a special where the lenses were half price so they put some in her old frames too, totalling \$2,000
- Dentist every six months, just a clean - \$90 each time



Nancy has mobility problems, osteoporosis and gets diverticulitis (very painful). She can't walk as far as she used and must pace herself, which she finds hard because she used to love walking and gardening. Her diverticulitis prevents her from driving the distances she used to as well and limits her sense of independence. *"So health issues curtail my life, it's a frustration but you just live with it and get on with things. You manage your life around it. You need to keep yourself mentally happy or you'd go crazy."*

A friend of her daughter's found a pain clinic and recommended it to Nancy. She has found this to be extremely helpful for managing her conditions. She visits fortnightly, and receives a variety of treatments, such as 'deep wave' (like laser treatment), acupuncture etc.

She finds her health issues chew into her money, and she doesn't feel as financially well off without an income. Initially her daughter was paying for the pain clinic, but eventually, through her GP, she was able to get MSD to cover the costs via disability allowance. She was surprised the GP didn't know about the pain clinic. The GP filled in the medical side of things of the disability allowance and although she did have to go into MSD she found the process easy. Her experience in DHBs means she feels she is aware of most of the social assistance available.

Nancy believes it's important people know about disability allowance, how to access services and where those services are. She believes the GP is really important as you get older, especially having the same GP who knows the patient's history.





Yvonne (Māori, 77)

Lives with her husband in a rented home. Retired completely, cares for her husband, no health insurance

Yvonne and her husband have been together for nearly 60 years and have two children, four grandchildren and eight great-grandchildren. Much of her time in her 50s was spent raising her mokopuna and even one of the great-grandchildren. Time then was quite difficult for her and her husband due to the loss of a son. Everything felt upside down and they made decisions that she feels were not very future focused. They were very active, playing sport, with her husband playing rugby league. However, the death of their son hit him hard, and he gave up sport around that time. A lot of their time was spent doing up houses and selling them on. While they did have times when they saved, they assumed they would retire owning their home and believed the pension would be sufficient to support them financially. Her husband broke his arm twice (he was a builder) which meant he couldn't work during those times. In addition, they used their pension, and went travelling overseas. They did contribute to KiwiSaver, which they cashed up later on to go to France for five months (cut short by COVID-19).

Life now is very quiet because her husband had a massive stroke, has issues with his thyroid, and prostate cancer. Yvonne has given up her cleaning job (three days a week for pocket money) so that she can help him get to appointments and pick up a lot of the running of the household. *"Until he got sick he could earn a little bit doing small jobs and it actually gave him extra spending money. Then he could go out. Now he can't earn, so can't go out, and that affects his mental wellbeing."*

Yvonne's eyes have been steadily getting worse, slowing her down and requiring new prescriptions every year. She has just been told she has macular degeneration which will need attention in the upcoming years. Neither of them has health insurance.

"It's drawing on our savings - we can pay our way, but it depends on how long we live. Every year I have to cut the budget. They need a higher limit on savings for the accommodation allowance. I know what we have isn't a lot, two funerals would be about it!"

Income:

NZ Super supplemented with some small savings. No disability allowance and haven't applied for it.

Expenses related to disability:

- Optometrist - \$60+, every year
- Glasses: ~\$1,000 every couple of years because progressive so she tries to avoid having to buy new ones and just sticks with the old frames if possible
- Eyedrops - over the counter
- Medication, prescription - mainly the prescriptions (\$10, \$15) monthly \$20/month
- Doctor (GP) visit costs - \$20 per visit at least every three months
- 4 x specialists - 3 monthly and several hospitals - no charge through hospital
- Carparking costs
- Walking stick
- Massager
- Was using free prescriptions at chemist warehouse but when her husband got sick she needed to be somewhere close who was familiar with their requirements



Paul (NZ European, 75)

Lives alone in a rented flat. Retired completely, no health insurance

Paul arrived in New Zealand from South Africa when he was 46 and in search of a good job. He has spent most of his life in sales, where he has had to establish good relationships. Unfortunately, he struggled to get work, and ended up driving buses which was paid badly with difficult hours and a stressful environment. His next job also turned sour, but he finally found work in Auckland. But the business was sold six months later as was the next company he worked for. Finally, he got a job in manufacturing which worked well for 3-4 years but the boss got cancer and his colleagues were lazy. The business was short-staffed because they couldn't attract anyone on the bad pay, and eventually it folded. He was 60 at that stage and was unable to find any more work. For five years he had to manage his money very carefully until he was eligible for NZ Super, and used up all the money he brought over from South Africa. When he was employed, he *'joined KiwiSaver much to the disgust of my employer'*, but never earned enough money to save for the future. When he left, he had saved \$3000 which was *'better than a poke in the eye with a blunt stick'*.

These days his principal interest is ballroom dancing. He sees it as essential to keeping him fit, he's good at it and 'it keeps him out of the pub'. When he can, he works on rebuilding his vintage car, but the guy he was working on it with has passed away. He also spends a lot of time writing to people overseas, one of whom is a long-term friend and others are people he's met through the vintage car register. He's happy on his own, but when health issues hit it can be very difficult. Financially, receiving NZ Super means he is living more easily and doesn't have to worry about every cent he spends although he is still very careful with his money. Fortunately, his rent is fairly cheap (\$365/week) because he gets on well with the landlord.

Up until 60 he felt very fit, but the combination of stress and being made redundant impacted on his health and he started developing arthritis and psoriasis. The arthritis affects his hands and wrists and is quite severe. He also had a brush with cancer. The medication he was taking for his arthritis affected his immune system. He now receives the disability allowance and an accommodation supplement. Temporary additional support tops up the rent that the accommodation supplement doesn't pay and helps with regular osteo treatments. He has had some good support from 'a government organisation' [he can't recall who], with new taps and drawer handles being installed for him. He thinks it was his GP who put them on to him. He relies on his car because the bus station is too far away, and he is unable to carry his shopping that far - fortunately MSD has been assisting him with repayment. The only health condition that he is struggling with financially is dental - he's been quoted \$500 for the dental work he needs but he is only eligible for \$300 per year and he wants to save that for emergencies.

"I found out about sources of support from my GP. She was very good and was the sort who could suggest these things. She got me on the disability benefit. Thanks to her I got started with help physically and financially. I've had a lifelong philosophy of 'it doesn't hurt to ask'... Most important thing, knowing where to go to seek help and what your entitlements are. Knowing what's available to you."

Income:

NZ Super, disability allowance, temporary additional support, accommodation allowance

Expenses related to disability:

- Osteoarthritis medication to stop progression: \$90 per 3 months
- No other expenses for the arthritis, more health related for other things.



Andy (NZ European, 65)

Lives alone in a home he owns, without a mortgage. Retired due to disability, no health insurance

Andy is separated from his ex-wife although they have remained friends – he doesn't have any children. He jokes that he is '*a man of many talents*', having a career that spanned engineering, truck driving in the Australian mines, driving harvesting machines, a painter and carpenter, and home handyman. Eventually he started his own business and supplemented his income with a disco sideline, busking at parties. However, he developed an immune condition, and the earthquakes ruined his entertainment business. He ended up working parttime in a more technical field, and also taught driving classes. Over this time, he used a revolving mortgage to pay his mortgage off as quickly as possible, by dropping all his pay into the mortgage. He didn't start contributing to KiwiSaver until he closed his business and became employed at the schools. By the time he was able to withdraw his money he had about \$26-27k.

Unfortunately, Andy was working at school up a ladder and the ladder collapsed, and he landed on one leg and face down. An MRI showed he had a labral tear in his hip and developing osteoarthritis. ACC declined to accept it as a workplace injury which meant he had to go on a waiting list for surgery. At the time he didn't challenge ACC because he was depressed and suffered PTSD from earthquakes. ACC covered him for \$340 week well down from the \$500/week he was earning. He also has arthritis in his wrists so he can't play music anymore, and his autoimmune condition means he must keep to himself more (particularly in light of COVID). He has had to curtail his driving business because of his injury, finding it hard to get in and out of the car. He has applied five times to get on the surgery waiting list for his hip and is on a 'waiting list for the waiting list'. The latest injury is a fall down some steps which injured his knee and ankle, something he believes happened because he was favouring his hip (ACC is currently covering this). He doesn't have health insurance. His wages have ceased because it's too painful to drive. He had to wait for a long time for his walker and it wasn't until he followed up with DHB that he was provided with one.

Financially Andy feels like he is coping, although he's sold a few things he doesn't need. He hasn't acquired any debt and is in fact preparing to undertake some minor home renovations. However, he is feeling very let down by the health system and desperately wants to get his hip repaired so he get back to living his life.

Income:

NZ Super plus a disability allowance (for the PTSD and leg injury).

Expenses related to his disability:

Steve uses a community services card and as a result his expenses related to his disabilities include:

- GP visits: \$20 (down from \$60 prior to turning 65)
- Script charges: \$19
- Physio visits: just started but about \$40 (which ACC tops up), likely to be up to six visits
- Sports massage: \$100 (once only)
- Chiropractor: \$30 (ACC tops up)
- TENS machine: \$100
- Gardener and house cleaner: paid by MSD (disability allowance)
- Currently working with the nurse at his GPs practice to get home help, and also have his place assessed for things like handrails



Jason (Chinese, 65)

Lives with his wife in a home that he owns, with no mortgage. Retired completely, no health insurance

Jason is 'virtually' retired and his wife (who is a couple of years older) is also retired. Jason is Malaysian Chinese while his wife is Kiwi. His wife suffers from manic depression so sometimes requires his support more than others. He feels that the neighbourhood they live in can be quite isolated, and because he is unvaccinated was unable to work during COVID-19 (he used to be a self-employed tradie). He likes to keep himself busy and enjoys hands-on type activities. For instance, he has built a greenhouse and is starting to grow vegetables.

In his early days he believes he made a big mistake of selling their home in New Zealand (for around \$200k at the time) and moving back to Malaysia. But the country experienced a severe economic downturn, and the US stock market crashed, causing him to lose all the money he had invested in it. *"I kick myself because I went back to look at the old house and it sold \$500,000 five years ago."* He returned to NZ with very little money, and at one stage was working in a factory to make ends meet. Eventually he found a fulltime job that had a government pension, but sadly was made redundant a few years later. He retrained and eventually became self-employed and got work through various agencies. After much effort he was able to finally pay off the mortgage just before he turned 65 (he cashed in his KiwiSaver to pay a chunk off). While Jason and his wife don't have a mortgage to pay, there are other expenses and they don't usually have much money left over for unexpected expenses because they are now 100% reliant on NZ Super.

Jason has become diabetic so tries to do lots of walking to counteract what he sees as an unhealthy diet (dictated in part due to their limited funds and the increasing cost of healthy food). He has experienced significant declines in both hearing and vision. While he is happy to just ask people to repeat himself, his wife is fed up with having to do so. Similarly, he is now struggling to read computer screens and knows he needs progressive lenses. At the time of speaking to him, he was trialling some hearing aids but knows he can't afford the \$4,000 that they cost, even with the Government subsidy, so is looking on TradeMe for some second-hand ones he has seen. He is hoping he might be able to get them for around \$500 for a model that is actually better than the ones he's been trialling. However, his audiologist has indicated he may face up to \$800 to get them programmed for his requirements. He has also been to the cheapest glasses store he can find (Specsavers) to get progressives. However, after waiting three months and six visits later, he is still dissatisfied with them and told them to keep them. They were going to charge him \$1,000. So now he is going to have to do some research about some other possible suppliers.

He would dearly love to be able to go back home to see his father who has dementia in time for him to still remember his son (he wasn't able to do this with his mother). But there is no way he can do that especially with these health expenses. He is hoping his son, who is in Malaysia, may be willing to help him financially to get home.

Income:

NZ Super

Expenses related to the disability:

- Hearing aids: at least \$4000, cheaper if through TradeMe
- Audiologist: ~\$800
- Glasses: aiming for less than \$1000



Andrea (NZ European, 74)

Single, lives on her own in a home she owns without a mortgage. Retired but does occasional temping, no health insurance

In her younger days, Andrea was involved in medical research, which involved working in various places. She had a companion, and they were both very focused on their work. Her life involved a lot of hard work and she found certain aspects of her role very demanding, often spending long hours on the computer. Eventually she found she was working longer than expected to achieve things and the strain was too much on her eyesight. Although she worked as a contractor she ensured that she contributed to KiwiSaver despite the lack of employer contribution.

Andrea found adjusting to retirement difficult, finding life somewhat boring. She has managed that by ensuring she always has a purpose for each day. *"If you don't create the purpose you end up in a slump. What have I even achieved today?"* Financially, she is feeling the pinch – everyday expenses are managed ok, but she does occasionally struggle when something big crops up. In those instances, she finds she may have to pay things off or put it on a credit card. *"I hate it. It's the pits. I don't like the feeling of debt, if I can do it without it I will, but things come up, like the car. Things that add up."*

Andrea has had several issues with her eyes – a while ago she had an operation on her corneas, and later on had cataracts so had the lenses replaced in both eyes. She thought she'd end up with much better eyesight, but unfortunately has found she's got about '80% of the eyesight of an average person'. As a result, she finds she has 'good days and grey days', the latter involving very cloudy eyesight. She also has to be extremely careful of the environment her eyes are exposed to. For instance, she used to love swimming but that is now out of the question, even with goggles. She needs to be careful about driving at night due to the glare of lights. If she gets anything in her eyes, she finds it excruciating and needs to go to the emergency department at Greenlane. Fortunately, she has developed a good relationship with a professor who has a team that he trains at the clinic.

"Financially, it's been a significant impact, I have to pay out on a constant basis. Vision is one of the most important parts of life. I can't walk up and down the stairs in the dark, so I have to make sure someone is there to help me. There are times I can't drive and have had to go on bus or taxi. Taxis aren't cheap. It confines you a bit, I used to roar around everywhere."

Income:

NZ Super, disability allowance and gets access to disability parking. She doesn't have a community services card.

Expenses related to the disability:

- Emergency clinic visits, free (although it may involve waiting for 5 hours)
- Private consultations with the specialist (\$200/300 per visit) when she can't get to him via the emergency department
- GP - \$20 to be referred to the Greenlane clinic
- Eyedrops - \$25 every month at least
- Special sunglasses and protection glasses (needed when windy) - \$500-600 per year for lens replacement and ophthalmologist consultation
- Devices with larger numbers (e.g desktop monitor, phones)
- Taxis when her eyesight is impaired



Kiri (Māori, 70)

Married, owns their home without a mortgage. Fully retired, no health insurance

In her 50s, Kiri and her husband were still working. Kiri came from a professional background, working in a range of roles in banking, administration, and customer services. Her husband worked in penal institutions. Kiri feels she had good management skills, and as the eldest of eight siblings could be “organised and bossy”. While she was quite driven at this stage, their children had left home, and she remembers starting to feel a bit tired. They were also increasingly thinking about holidays and having a bit of downtime. They gave retirement some thought but didn’t have specific plans. They were putting money aside, and started contributing to KiwiSaver as soon as it came out.

Kiri continued to work parttime in retail after 65, mainly for the opportunity to interact with others, but also to supplement their retirement income. It meant she could go for a ‘bit of pampering or get my hair done’ without worrying about spending a bit of money. However, with COVID-19, she and her husband started to reassess whether they wanted to continue working. Instead, they purchased a motorhome and drove around the country visiting whānau. It gave them a chance to get away from all the stress of COVID-19 and see the country. Kiri is now feeling in a great place with a purpose – helping their mokopuna grow up. In their working days, they didn’t feel they had the time for each other but now they do, and she feels very grateful. *“It’s a shame you have to get to retirement to have a relationship with each other.”*

However, recently she had a fall, the second time in a short period of time. She’s always been an active walker but feels her coordination and balance have really declined. She doesn’t have the flexibility she used to and now must get down the stairs sideways. She’s lost a lot of confidence and finds herself looking for railings and moving very carefully. Her doctor has told her she needs to lose weight and has directed her to a dietitian. She has explored gyms, strengthening devices for the home and other mobility related activities (including an online yoga course) but has yet to find something that works for her.

Income:

NZ Super, earnings from occasional work

Expenses related to disability:

- GP - \$20 per visit
- No other expenses yet related to her falls and impaired coordination other than the yoga subscription

Kiri is probably our least impacted financially out of the case studies because she hasn’t had to deal with dental, hearing or eye concerns yet and is not experiencing uncomfortable mobility.





Trudy (NZ European, 76)

Lives alone in a home she owns without a mortgage. Retired but very active volunteer, no health insurance

In Trudy's 50s, she was working for Ministry of Education, and commuting from her home. This represented a big change because prior to that she had been teaching. Although widowed and on a single income, she had committed to putting her children through university so was facing quite large costs at the time. She was very aware she should be saving for retirement but found this difficult while paying out for big expenses. She'd been earning too much to get any access to benefits but was also trying to pay off her mortgage. Sadly, having worked hard to save all she could, her nest egg was embezzled by her financial advisor. Eventually she had to say goodbye to about \$50,000. Nevertheless, she also had KiwiSaver and started seriously saving, eventually ending up with about \$120,000 put away.

Trudy loves being retired, although she worked until she was 70: *"My purpose in life was to retire, I'm so happy to be retired. I have a happy life. Except financially and health-wise."*

She continues to live on her own, in the house she raised her children. She loves gardening, but it's getting tricky now because of the herniated disc in her back, and arthritis in feet and hands. Regardless, she goes to the gym and tries to keep fit. She also considers herself a 'professional volunteer', is active in her church, and is also a soroptimist (belongs to a service group working for the welfare of women and girls). These activities provide lots of community connection.

Remarkably, she says she was recently diagnosed as having 'second sight', and no longer needs glasses for driving. She bought hearing aids when she retired and says they're wonderful. Trudy receives the disability allowance but thinks she may be eligible to receive a bit more than currently. However, she believes she has to go into Work and Income and she is too scared to. When asked if she has talked to her GP, she said she also hates going to the doctor!

"I also get a disability allowance, got it at 70, I'm now 76, but I have never been back to say that my expenses increased dramatically. MSD is an intimidating building to go to. I know I'm going to have to, I know I should. But there should be a separate area for superannuitants. It's intimidating because of the guards at the door. I've only been there once before, it was just the most awful experience."

"Not enough people understand how insecure a lot of elderly people are. Take me not going to WINZ. I actually think with superannuitants, there should be home visits. That initial visit could have been much better when I was in my own home. That person who initially set you up could ring later and ask, has anything changed, not just send an email. Surely, I could have my meeting with WINZ through zoom?"

Income:

NZ super, a little bit of interest from KiwiSaver and term deposit, disability allowance.

Expenses related to disabilities:

Hearing aids: \$6,590 after a government subsidy (gets lifetime care, adjusted and hearing tests at no cost). But would need to pay for new ones if necessary.

Arthritis

- Painkillers, on paracetamol and codeine. "Just have to manage the pain, arthritis is in all the bones in feet, hands and wrist. I'm quiet stoic and just deal with it."
- Walking stick

Back

- Was offered surgery many years ago (under ACC) – chose not to have surgery

Glasses

- Optician (glasses to help night driving) - \$400
- Petrol costs, 2 hour drive (her optometrist has moved from Gore to Dunedin)



Gary (NZ European, 76)

Married, lives in a home they own without a mortgage. Retired and cares for his wife, no health insurance

Gary worked for a long time as a firefighter, initially as a volunteer, then into the permanents until 2007, when he had a knee replacement that was unsuccessful. After that he went into volunteer role for 10 years as operational support. Financially, it was very hard because the pay was poor, and he used to take secondary jobs (like transport) to supplement his income. *"The days off from fire station was spent supplementing my income. I had to forfeit a lot of things although my wife's income helped."* As a result, it was hard to save but the fire service introduced an optional super scheme which he signed up for. Once he retired, he withdrew the lot and it's still sitting in the bank. They intend to move to a retirement village and have paid a \$3,000 deposit.

Gary feels his health went downhill pretty quickly. Both knees are bad despite one of them being replaced. Fortunately, he had a CT scan about two weeks ago, and since then the hospital has told him he is on the list for two replacements since it appears they may need to redo the first knee. Gary also has emphysema from his time as a firefighter which he expects will decline considerable. He's worn hearing aids for the last seven years, the hearing loss a result of exposure to noises such as pumps and sirens. His wife has developed multiple myeloma, and he spends a lot of time doing things for her (e.g. housework, washing, helping her shower and dress, looking after the house). While the supermarket is only a few minutes' walk away he drives because of his knees. His grandson (13) looks after the lawns, and they have a lady who comes in to do gardening which WINZ contributes to. He's trying to keep the house as well maintained as possible because he doesn't want it to get rundown before selling. He has to take pain medication so he can do this. However, he does try to have the odd afternoon playing pool with his ex-firefighter mates. Gary doesn't have health insurance. *"While I can still walk, I don't see the point going private when I can go through the health system. But I will have to pay for the dentures I have to have made, and that will cost about \$3,000."*

Income:

NZ super, interest from pension, disability allowance of \$1,450/year which is paid into his pension. He has recently checked WINZ and believes he could access medical fees (\$47 quarterly), and prescription charges annually (\$100/annually).

Expenses relating to the disabilities:

- Pain medication (paracetamol, gabapentin and codeine): free
- Knee: \$19 for GP
- Scripts \$19. Go once month/6 weeks
- Can't remember how much paid for hearing aids
- Audiologist once a year, can't remember cost

"Superannuants are behind normal people in the country as far as income. It's a tight budget. The money you have isn't replaced because we aren't working."





Gavin (NZ European, 76)

Married, lives in a home they own without a mortgage. Retired completely, no health insurance

Originally from South Africa, Gavin worked his later years in New Zealand as an IT project manager, a profession that was predominantly desk work. He says he has always been a 'calculating type of person' and made sure to plan for retirement. When KiwiSaver came out, he contributed the maximum he could. During those years, he felt fit with no serious problems with his health at all. However, by 64, he got to the stage where he had enough of working so quit his job and funded himself for a year. Having had an active interest in real estate, he took real estate exams but found he 'wasn't a good estate agent'.

Now in his retirement he has plenty of hobbies, enjoying gardening, woodwork, archery as a sport, and taking the dogs out walking. However, following a heart attack while walking, his doctor has told him he needs a stent which will cost him \$12-13,000 so he is reliant on the health system which is proving difficult. At the moment, he has been given some tablets with the instructions to 'see how you go', which he feels is just putting off the inevitable. He hasn't had any indication of when he might have surgery. He had a cataract operation a while ago, but his near sight is getting worse and he needs glasses to read. In addition, his hearing has deteriorated quite a bit, especially in crowded rooms. He has yet to get hearing aids because he understands the cost to be high (~\$7,000). His ability to go private has eroded significantly due to cost-of-living increases, with power and insurance up 50%. He doesn't have health insurance because it would cost around ~\$900 a month. *"If the health system doesn't get onto it, I'll have to pay for it myself. I'll have to try to get the funds from somewhere. I spent a lot of time paying my tax, I'd like to get something for it."*

Income:

NZ Super, KiwiSaver

Expenses related to the disability:

- Prescriptions: (\$5 per script)
- GP: <\$20 per visit
- Specialist visits \$500 for one visit (dental), \$200 per year (eye specialist)
- Optometrist: \$500 / year

Overall, Gavin feels like he is coping with the day-day expenses relatively well, but it's the larger one-offs that are throwing him.

"I need to get my heart fixed up, I don't want to drop dead, they need to get the health system sorted out. The procedure is only 20 minutes."





Lisa (NZ European, 72)

Lives alone in her own home without a mortgage. Retired completely, has health insurance

Back in her 50s, Lisa was living in house with her husband, while her daughter lived in England and her son was in Australia. She was working full time, and busy paying the mortgage off. Her time was very busy, initially working for a DHB and subsequently in radiology. Any spare time or money was used for travel, where they went away for weekends. She was active, playing tennis and enjoyed gardening. She made sure she contributed to KiwiSaver, although not initially because her husband passed away the first year it was introduced. Once back at work she signed up straight away and belonged to a growth scheme. She happily states she got far more than she thought she would once she retired. As a disciplined saver she also had term deposits, and at one stage put that into KiwiSaver too. She also had health insurance, and due to her experiences working in the health system has ensured she has continued that up to now.

These days, Lisa lives alone in home she's had for 45 years. She is active with her children and grandchild and loves gardening and cooking. She worked until her daughter had her first child, but she stopped because she wanted to spend time with the grandchild. She still does a lot of walking with friends. Although she still has her KiwiSaver, it's not performing well, and she is trying to sit tight and not withdraw it. These days, her health insurance has gone up but she's managed that cost by increasing the excess to \$1,000 which keeps her premiums lower.

She's very glad she still has health insurance because she's had to use it a number of times. The first time she twisted her ankle on a tramp, five years ago. ACC declined to help because the position was that the cause was osteoarthritis that had started many years ago. She was able to have the ankle fused successfully by going private (\$30,000). However, 18 months ago she began experiencing groin pain, and after going to a physiotherapist, an MRI found she had bad arthritis in her hips. Both were replaced about six weeks ago (\$40,000). She is back walking but not to the stage she'd like to be. She's also used her health insurance for chemo and radiotherapy for breast cancer. Lisa also has hearing aids which she has paid for herself.

"I have a friend who went through public and they wouldn't discharge her until they had everything in place for her. So she spent two weeks in hospital until occupational therapy could get to her home. I think that's false economy! If you go private, you are given a list that you are expected to sort out yourself. When it's private it's efficient because there is a cost involved. That's not happening in our health system – because it's nobody's money in particular."

Income:

NZ Super, KiwiSaver and term investments

Expenses related to disability:

Health insurance - \$400/month (NIB) surgical – two separate policies – one surgeon and one for GP and x-rays, CT (not mammograph), not diagnostic or skin check.

Ankle

- ACC initially paid for MRI
- Scooter - \$200/months for three months
- Crutches \$70/week

Hips

- Physio for hip initially over the year – initially ACC (\$35 part charge) fortnightly for six months. Would have been \$90 per visit without ACC
- MRI: ACC (would have been \$1,200 otherwise)
- X-rays - \$90-120 without ACC
- Surgeon: \$300 (not under policy because it doesn't pay for diagnostic until the operation)
- Physio would have been \$90 without ACC = now having to pay that (will get some back from insurance)
- Transport: Friends picked her up
- Toilet seat - \$35/week but she also was able to borrow one

Breast cancer

- Mammogram and ultrasound through public
- Surgery and treatment: paid for by health insurance
- Follow up appointments with specialists (breast cancer) mammography and topography- \$850-1000. Once a year

Hearing aids:

~\$10,000.

Dental:

- Crowns: \$1,000 paid for by insurance

Appendix 1. Recruitment screening questionnaire

Thank you for starting this survey. You do not have to answer the questions or complete the survey if you prefer not to.

Which age group do you belong to?

Please select one only

Under 18 years	1	CLOSE
18 - 34 years	2	
35 - 54 years	3	
55 - 64 years	4	
65 - 69 years	5	continue
70 - 74 years	6	
75+	7	
declined	6	CLOSE

Thinking about your life now, which of the following have you experienced increased difficulty with compared to your life prior to 65?

	No change since turning 65	Slight increase in difficulty since turning 65	Moderate increase in difficulty since turning 65	Significant increase in difficulty since turning 65
Seeing			Must code at least one	
Hearing				
Walking				
Dexterity (using your hands)				
Flexibility (e.g bending down, reaching up)				
Personal care (e.g. showering or dressing)				
Psychiatric (e.g. dementia, Alzheimers)			Continue but do not recruit	



Overall, how much financial impact have these areas of difficulty had on your life?

Think about assistive devices (e.g. hearing aids, walkers), types of medication/surgery, having to make modifications to your home or your vehicle, investing in certain types of technology, hiring people to help you, taxis / ubers, etc.

No financial impact	1	close
A slight financial impact	2	
A moderate financial impact	3	
A significant financial impact	4	
Don't know	5	close

How would you rate your current financial situation?

Please select one only

Very poor	1
Poor	2
Neither poor nor comfortable	3
Comfortable	4
Very comfortable	5

To what extent do you rely on NZ Superannuation to provide you with an income?

Please select one only

NZ Superannuation provides all of my income	1
NZ Superannuation provides at least two thirds of my income	2
NZ Superannuation provides at least one third of my income	3
NZ Superannuation provides less than one third of my income	4
I am not eligible for NZ Superannuation at all	5
Don't know	98

Which of these best describes you?

Please select one only

I live in my own home with a mortgage	1
I live in my own home without a mortgage / freehold	2
I live in a rented home / flat	3
I live in a retirement village	6
I live with other family members in their home	7
Something else (rent free, boarding house, hostel, etc.)	8



Which is your gender?

Please select one only

Male	1
Female	2
Another gender (specify, if you'd like to)	3

Which of the following best describes your living situation?

Please select one only

I live together with my spouse / partner	1
I live together with my spouse / partner and child / children	2
I live with my child / children	3
I live with my parents	4
I live alone	5
I share a dwelling with other grown-ups (e.g. flatting, share with a friend or equivalent)	6
Other (please specify)	7



Which town or city do you live in or live closest to?

Please select one only

Ashburton	1
Auckland	2
Blenheim	3
Christchurch	4
Dunedin	5
Gisborne	6
Greymouth	7
Hamilton	8
Hastings	9
Hutt Valley	10
Invercargill	11
Kaikoura	12
Kaitia	13
Masterton	14
Napier	15
Nelson	16
New Plymouth	17
Otorohanga	18
Palmerston North	19
Porirua	20
Queenstown	21
Rotorua	22
Taihape	23
Taupo	24
Tauranga	25
Thames	26
Timaru	27
Wanaka	28
Warkworth	29
Wellington	30
Westport	31
Whakatane	32
Whanganui	33
Whangarei	34



Which of the following ethnicity groups best describes you?

Please select all that apply

NZ European	1
NZ Māori	2
Samoan	3
Cook Island Māori	4
Tongan	5
Niuean	6
Another Pacific Island group	7
Chinese	8
Korean	9
Indian	10
Another Asian group	11
Another European group	12
Another ethnic group	13
I'd prefer not to answer	14

Thank you for your answers. The project we wish to conduct involves people aged 65+ who have experienced some financial impact from a late-onset disability.

Having gone through this screening questionnaire, do you still wish to take part in an interview? If you are selected, we intend to discuss:

- What life was like for you in your 50s;.
- Your preparations (if any) for retirement;
- Your current financial situation, including sources of income (we won't ask about \$ amounts) and expenses (approximate \$ values for expenses that relate to your disability / long-term health condition);
- Sources of financial assistance you currently access.

Yes	1
No thank you	2

If you are selected for this project, would you prefer to be interviewed:

- ☐ Remotely / via Teams
- ☐ Via phone
- ☐ In person (in Auckland only)
- ☐ I don't want to take part in this project



Appendix 2. Discussion guide

1. Introductions:

- Aim of the research, who it's for, how it will be used
- Confidentiality, no right or wrong answers, can decline to answer questions
- Permission to record

2. Tell me a bit about yourself [build rapport]

- If your spouse or a good friend described your personality to me, what would they say?
- How do you enjoy spending your time?
- Who do you live with? And what sort of house is it?
- Do you own your home, or do you have a different living situation?

3. Let's think back to when you were 50-55. What were you doing around this time? [aim is to understand how financially prepared participant was going into 'retirement']

- Did you own your home?
- Did you have kids? Were they living with you?
- Did you travel much?
- Were you working for pay?
- How did you feel about life at this time?
- And how were you positioned financially?
- Did you think much about the future?
- Did the concept of retirement feature?
- Were you preparing for it in any way? If so, what sort of things were you doing?

4. And how are you feeling about life after 65?

[aim is to bring participant into the present and gradually introduce the topic]

- What do your days look like these days?
- In what ways are they different to those days back when you were 50-55?
- How do feel about your financial position?
 - Anything you were pleased you planned for, or wished you had done slightly differently?



5. When you were recruited for this project, you indicated you had developed a few physical conditions after you turned 65. Would you mind telling me a bit more about this? Just whatever you are comfortable with.

- Participant to lead discussion.
 - Note feelings, tone, perspective about life going forward
 - Thank participant for sharing their thoughts

6. I'm now keen on understanding a little bit about your financial situation. *[central objective to the research]*

- Where does most of your income come from these days? I don't need to know amounts, just general sources.
 - Probe any income relating specifically to their condition or disability (e.g. disability allowance, ACC etc)
- And what would your biggest expenses be?
 - Which of your expenses are expected, and which have been a bit of a surprise?
 - (if not mentioned) Which, if any, of the expenses relate to your... [disability / condition]...?
 - I'm keen to make sure we capture all those expenses. What about..
 - Transport, medication / health, devices, home assistance, mobility, assistive technology, modifications to your home or vehicle
 - If you are willing, are you able to give me some approximate amounts for these things? You are welcome to decline to do this.
 - What assistance (if any) do you get for those specific expenses (e.g. community services card, grants / funds)?
 - Probe on glasses and hearing aids
- Financially speaking, what sort of impact has your... had on your ability to live the sort of life you want?
 - To what degree has your ... impacted on your overall financial position compared to prior to having ...?
 - And what sort of financial impacts have resulted? Probe:
 - not socialising / doing things you'd normally enjoy, having to go without;
 - greater reliance on family;
 - inability to earn an income;
 - the need to borrow money or use BNPL-type sources of credit;
 - selling the home, selling other assets;
 - changed intentions for bequests

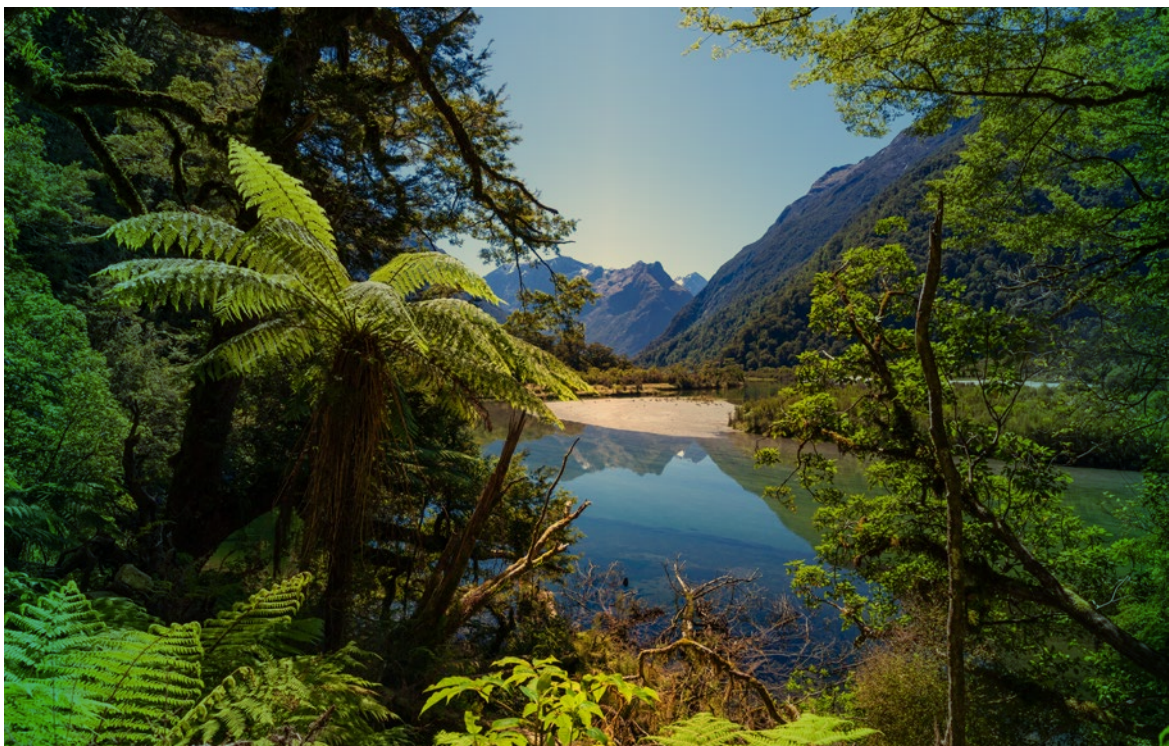


7. In terms of accessing financial assistance who are you aware of that can help?
[wrapping up, providing support to the participant]

- Have you approached them? If so, what was the outcome?
- These are some of the places that can offer some assistance [Jo to briefly describe what they do]:
 - Christians Against Poverty (CAP) – free financial plans, negotiation with lenders, financial coaching and courses
 - Salvation Army – food, loans, housing (community or social housing)
 - Good Shepherd – specially for women, free financial plans, negotiation with lenders, financial coaching
 - MSD (Work & Income) (e.g. getting a disability allowance, a community services card, or accommodation allowance, special needs grants)
 - Ministry of Disabled People (e.g. for home or vehicle modifications they can fund, and source of advice)
 - Aged Concern (e.g. counselling, mobility assessments, health promotion, information and advice)
 - Carers NZ (focus is more on supporting those who provide care to others)

8. I'd like to wrap up our chat now. Thinking about what we've been talking about today, what are some of the most important things you want me to take away from it?

- And do you have any questions for me?
- Provide incentive and leave list of contact details for above services.



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