

New Aged Care Act Rules consultation – Release 2b – Funding of Aged Care Services

Spinal Cord Injuries Australia
Submission February 2025





About SCIA

SCIA is a for-purpose organisation working for people living with spinal cord injury (SCI) and other neurological and physical disabilities. SCIA was founded by people with SCI over fifty years ago; people with disability make up over 35% of our staff, 25% have an immediate family member with disability and the majority of our Board live with SCI.

SCIA is national and member-focussed, serving over 3,000 members made up of people living with disability, their family, carers, researchers, and other professionals in the sector. SCIA's Systemic and Representative Advocacy Team work closely with our members to understand their aspirations and concerns and to promote full inclusion for our members living with disability.

About Spinal Cord Injuries

A spinal cord injury (SCI) is a complex and permanent disability. At least one new SCI happens every day in Australia, making an approximate total of 20,800 Australians with a SCI.¹ Accidents such as SCI can happen to anyone at any time and 40% of new SCI's are in people who are aged 60 and above.

People with complex SCI such as quadriplegia who enter residential aged care facilities have substantial personal care and nursing support needs, that can, in some cases, amount to over 8 hours of daily nursing and personal care.

SCI is a complex physical disability that limits an individual's ability to use their body. However, it does not limit intellectual capacity or community engagement and does not well align with the Aged Care Legislation's language of 'frail and aged'. The people within this cohort, are parents and grandparents often just entering retirement and are deserving of a full life either in the community or within a residential aged care facility.

Introduction

Many people who enter a residential aged care facility do so against their preference because of inadequate Support at Home funding (outlined in our December submission to release 2A). Such people, if it were not for their disability, would not need to access aged care services for many years.

It is of paramount importance that older people with complex disability such as SCI who enter a residential aged care facility, either by choice or necessity, are supported to:

- a. Access their preferred facility
- b. Participate and maintain a healthy life

The Aged Care Bill and associated changes does not include sufficient funding allocations to residential aged care facilities for people with complex disabilities such as SCI.

The Aged Care Royal Commission recognised this inequity and, in recommendation 72 entitled "Equity for people with disability receiving aged care" stated: "By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions".²

¹ SpinalCure Impact Report 2022

² Royal Commission into Aged Care Quality and Safety (2021). Final Report: Care, Dignity and Respect



This recommendation is most used to discuss Support at Home however applies equally to people who live in residential aged care facilities.

In 2020, the average annualised support in residential aged care for those with high needs was approximately \$104,000 with a maximum capped amount (inclusive of personal contributions and government contributions) of \$139,000 a year.³ This compares to the average high level specialist disability accommodation NDIS funding of \$199,601 with the amount for the highest impairment category having an average of \$493,170 a year.⁴

The costs outlined above are indicative of the access and the amount of care provided. Clinicians and other professionals who provide care in residential facilities, working within the existing funding model, do not have the capacity to adequately support people with complex disability. People in residential aged care are either:

- a. Turned away from multiple facilities due to their shifting discharge dates as well as the complexity (and cost) of their care needs. This blocks beds in hospitals as people wait for discharge and costing approximately \$1200 per day.
- b. Offered a place but need to constantly advocate for their care needs such as complex bowel care.

Access to appropriate and safe care is a minimum requirement for all people with disability in residential aged care.

SCIA recommends either an additional supplement or other incentive to ensure that people with complex disability can access their preferred residential aged care facility. We also attach our Policy Brief as Appendix A to give a wholistic view and provide case studies of the barriers facing people with complex disability accessing residential aged care.

Member Consultation

SCIA has been working with our engaged group of members aged 65 and over to discuss their *My Aged Care* questions, concerns and recommendations. Our submission and Policy Brief are based on feedback and recommendations through this consultation process.

Members who have discussed with us the barriers they experienced entering residential aged and report a lack of availability in preferred facilities because of complex care needs that are often more than the highest funding amount and the risks associated with a power wheelchair in a facility. Together this makes a significant disincentive to take older people with complex disability.

Members report:

- Being rejected from multiple facilities
- Having to relocate to areas far away from their family and community.
- Being told they cannot enter a facility without a confirmed entry date despite this being difficult when exiting from a rehabilitation environment.
- Having to remain in rehabilitation facilities for much longer than required at a cost to their personal wellbeing and to government as beds cannot be utilised for new patients.
- A lack or appropriate care, not necessarily due to a lack of knowledge but due to a lack of staff to provide care.

³ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

⁴ ibid



Nursing and Personal Care Requirements

For members with high level SCI/ quadriplegia nursing and personal care requirements may include pressure care, transfers, seating care, bowel care, shower assist, skin assessment, dressing support, feeding assist, continence assist, cough assist, medication assist, bed positing and ongoing breathing support.

The following case study about Maxwell is illustrative of how high clinical care needs lead to multiple rejections from aged care facilities for people with SCI.

Maxwell is a 68-year-old man who had a fall from height leading to a high-level SCI. At the time of his accident, Maxwell lived alone at home and worked in a professional senior management role. However, due to his age Maxwell was ineligible for NDIS and only eligible for My Aged Care. Maxwell's Home Care Package was insufficient to support his care needs, his house and assistive technology would have been funded at his own expense. Despite his mental acuity Maxwells only discharge option was to a residential aged care facility, a choice Maxwell would not have had to make were it not for his accident.

Maxwell's care needs, include a complex assisted manual bowel routine, hoist transfer, assistance with all personal care and activities of daily living, regular chest physio and manual cough assist. Maxwell remained in hospital for 18 months because he was declined a place in over 110 aged care facilities due to his high clinical care needs.

Arguably Maxwell should never have had to live in a residential aged care facility however with this being his only "choice", facilities must be funded sufficiently to accommodate people with complex physical disability.

Chapter 7—Funding of aged care services—Commonwealth contributions

Chapter 7, Part 7, Divisions 1 and 2 covering person-centred and provider-based subsidies allocates insufficient funding across all Modified Monash categories for people with complex disabilities requiring the level of care outlined in the above section.

Provider-based subsidies and supplements offer scope within the Rules to consider targeted supports for categories.

Recommendation

Consultation with residential aged care providers is essential to determine the true cost of supporting people with complex disabilities including a risk analysis regarding the use of power wheelchairs.

The resulting costs must be reflected either in the form of a higher 'level' of payment or an additional subsidy or levy such as within the Provider-based subsidies and supplements outlined in the Aged Care Legislation Rules, payable to facilities that accept people with complex physical disability.

Appendix A – SCIA Policy Brief, Achieving equity for those aged 65 and over.



POLICY BRIEF

Achieving equity for people who acquire disability at 65 or older.

If.you.acquire.a.disability.such.as.Spinal.Cord.Injury.at.age. 20. you.will.receive.tailored. supports.that.enable.you.to.participate.in.your.communityi.lf.you.acquire.a.disability.such.as. SCI.at.age. 20 or.above? you.will.not.have.access.to.sufficient.supports.to.for.basic.care.such. as.transferring.into.and.out.of.bedi.This.glaring.inequity.needs.our.urgent.attentioni.

Introduction

Acquiring a complex disability, has lifelong effects. However, with appropriate support people with disability such as Spinal Cord Injury (SCI) or Acquired Brain Injury (ABI) can continue to live fulfilling lives.

People who acquire disability under the age of 65 have access to needs assessed support in the National Disability Insurance Scheme (NDIS) however, those who acquire disability at or after 65 are, by legislation, excluded from the NDIS and directed to My Aged Care. Many such people, if it were not for their disability, would not need to access aged care services for many years.

In 2023, The Hon Anika Wells, Minister for Aged Care stated, "Older Australians who have contributed so much to Australian society rightly expect to be well supported in their frailer years." Consequently, people with complex disability had high expectations for the new Aged Care Act and associated supports. However, although the increased funding for assistive technology is welcomed, the funding directed to personal care is still insufficient for a person with complex disability to transfer into and out of bed and visit the bathroom seven days a week.

At least one new SCI happens every day in Australia, making an approximate total of 20,800 Australians with a SCI.² It is estimated that one in forty-five Australians has an Acquired Brain Injury (ABI)³. Data about significant acquired disabilities such as SCI and ABI collected over the past decade shows that people are increasingly having their injuries later in life. In 2023, 40% of

¹ A New Program for In-Home Aged Care, Discussion Paper, 2022

² SpinalCure Impact Report 2022

³ Australian institute of Health and Welfare, Disability in Australia: acquired brain injury, Bulletin 55, December 2007

Australians who acquired a SCI did so when over the age of 65⁴ and people over 65 are twice as likely to have an ABI that limits their ability to participate in the community.

The Aged Care Royal Commission recognised this inequity and, in recommendation 72, entitled "Equity for people with disability receiving aged care" stated: "By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program, daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions."⁵

Recommendation 72 has not been acknowledged in the new Aged Care Act or associated Rules which solely refer to "frail and aged" persons. Consequently, aged care supports are not funded or tailored to meet the needs of older persons with complex disability.

People aged 65 years or over who acquire a complex disability and who have insufficient personal funds to supplement their ongoing care needs at home are forced into residential aged care.

Because of their complex disability, older people, particularly those in power wheelchairs, are routinely turned away from residential aged care facilities. Once in residential aged care, older Australians often face the added injustice that personal care and nursing supports otherwise targeted for the "frail and aged" are insufficient due to their complex disability.

The Aged Care Act Rules are being developed. SCIA members call on the Australian Government to implement solutions to address the inequity faced by those 65 and older who acquire a permanent and complex disability.

Disability Supports in the Community

Under the new Aged Care Act people with complex disability do not receive sufficient personal care funding to be transferred into and out of bed each day.

Under the NDIS

- People with complex disability such as quadriplegia have tailored disability supports⁶
 personal care and capacity building supports as well as assistive technology and home
 modifications.
- A person with complex disability such as ABI or quadriplegia, receives approximately 50 hours of personal care per week equating to 7 hours per day. Supports enable a person to transfer into and out of bed, toilet and shower, enjoy meals and participate in the community⁷.
- There are no co-contributions for personal care (or any) support.

Under the new Aged Care Act

⁴ Data provided on request by the NSW Agency for Clinical Innovation.

⁵ Royal Commission into Aged Care Quality and Safety (2021). Final Report: Care, Dignity and Respect ⁶NDIS Spinal Cord Injury Summary Insights, June 23

⁷ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

- People with complex disability such as ABI or quadriplegia can access a Level 8 Support.at. Home package that provides a maximum number of 18 hours of personal care per week equating to 2.5 hours of care a day. These supports are insufficient to cover basic care needs such as transferring into and out of bed, toilet and shower.
- Older people are required to co-contribute between 5% for a full pensioner and 50% for a self-funded retiree for independence supports (inclusive of personal care) with lifetime cap of \$130,000.
- Prior to the new Act, a person with complex disability could receive a maximum level 4, Home.Care.Package.amounting to approximately 14 hours care a weeki.Whilst the additional 4 hours weekly care under the Support.at.Home program is welcome, it does not translate into sufficient care to remain at home.

Those 65 and over with permanent complex disability, and their loved ones, are faced with heartbreaking decisions to finance basic personal care needs, such as toileting and transferring to and from bed, including:

- selling their homes;
- partners returning to paid employment following retirement;
- moving into residential aged care; and
- relying on elderly partners or family for complex personal care needs.

Alternatives such as these place extreme strain on individuals and their families.

A 2021 study conducted by Leading Age Services Australia found that "There is a substantial difference in support between aged care and NDIS programs. This appears to reflect differences in the hours of care available, though differences also exist in the level of support for reablement,

Shauna.and.her.husband.Steve.are.both.active.members.of.their.community.who.worked. until.retirement.age.saving.for.a.shared.future;.Shauna.sustained.C0.quadriplegia.following.a. cycling.accident;.Shauna's.disability.means.her.legs.are.paralysed?her.bowel.and.bladder. functions.are.impaired?and.she.has.limited.use.of.her.arms.and.hands?otherwise?she.is. mentally.fit.and.active;.Because.Shauna.is.over.20?she.is.supported.through.My.Aged.Care. (something.she.would.not.need.to.access.were.it.not.for.her.disability).with.a.Level.0.Home. Care.Package;.Shauna's.package.only.covers.her.morning.care.for.six.mornings.a.week;. There.is.nothing.remaining.in.the.package.to.cover.the.seventh.morning?evening.care? nursing?respite?allied.health?or.equipment;.Most.of.her.care.is.provided.by.Steve?who.is.20.years.old?or.purchased.at.their.own.expense;.As.Steve.ages?Shauna's.only.alternative.will. be.to.move.into.residential.aged.care;.Steve.and.Shauna.have.been.advocating.for.adequate. support.for.over.76.years.and.feel.utterly.disregarded.following.a.lifetime.of.hard.work.and. contribution;.

 $\verb|\noindent | Names.in.case.studies.have.been.changed.to.respect.privacy.of.members||;|$

social engagement, behaviour support, care management and assistive technology." This discrepancy has not changed with the passing of the new Aged Care Act.

Recognising that people with complex disability want to remain at home, My Aged Care commissioned modelling in 2023 to compare the costs of personal care at home compared to personal care in residential aged care. The findings of the study have not been released however on 14th December 2023, the Assistant Secretary, Support at Home Reform Branch, Nick Morgan said that 6% of older people could safely remain at home for equal cost.

SCIA understands the fiscal pressures on the aged care system with an ageing population. However as outlined in the case studies within this brief, the inequity between those under and over 65 is unacceptable.

SOLUTION 1: In support of our members over 65, SCIA supports full equity of disability supports with the NDIS. The two-tier system we have created amounts to age discrimination and should be immediately addressed.

In 2011, the Productivity Commission recommended the establishment of two schemes: the National Disability Insurance Scheme (NDIS) and the National Injury Insurance Scheme (NIIS). The NIIS scheme, was only partially established. Whilst the motor and workplace injury streams were established, the general injury stream was never developed. Failing to deliver the completed NIIS has been a contributing factor in the increased costs of the NDIS⁹ and left those with complex permanent disability acquired at 65 and over inadequately supported through My Aged Care. SCIA members call on the Government to urgently address this inequity through either:

- a. Inclusion for those with complex disability in the NDIS
- b. Full implementation of the NIIS, through the addition of a general injury stream.
- c. A tailored supplement paid through the My Aged Care system through an uncapped needs assessed supplement for those who would qualify for NDIS support if under 65.

If solution 1 is not considered, SCIA requests implementation of the lower cost solutions proposed below.

SOLUTION 2: Development of a mechanism for determining tailored supports sufficient for a person over 65 with complex disability to be afforded the minimum dignity allowing transfer into and out of bed and use of the bathroom daily. This could be done through one or more of the following mechanisms:

- a. A tailored personal care payment to people in categories identified in 2A, 211B (2) of Release 2 of the Rules sufficient to enable the transfer into and out of bed and use of the bathroom daily.
- b. Release and further examination of the 2023 Deloitte modelling to understand the true cost difference between care at home and care in residential aged care. At a minimum, the 6% of people who could 'safely' remain at home for equal cost should be able to do so. Additionally, an older person should be afforded the 'dignity of risk' that allows them

SCIA: POLICY BRIEF | Achieving equity for people who acquire disability at 65 or older

⁸ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

⁹ Completing the National Injury Insurance Scheme, A Key Sustainability Measure for the NDIS, Submission to the NDIS Review, Young People in Nursing Homes National Alliance, 2023.

to opt to use the funding that would be allocated to them in a residential aged care facility in their home. This is, in practice, already occurring as older people opt to rely on elderly partners to make up the short fall in funding.

In 2020, the average annualised support in residential aged care for those with high needs was approximately \$104,000. 10 It seems reasonable therefore, to allow the older person to use the amount that would have been allocated them in residential care in their own home if that is their choice.

c. To reduce the inequity of support for self-funded retirees who use their personal savings to fund basic personal care, waive co-contributions up to an amount of personal care that enables a self-funded retiree to transfer into and out of bed and use the bathroom daily.

Assistive Technology and Home Modifications

Under the new Aged Care Act people with complex disability have improved access to funding for Home Modifications and Assistive Technology however still significantly less than those in the NDIS.

Australia's Disability Strategy 2021-2031 requires that: "People with disability have access to a range of supports to assist them to live independently and engage in their communities." This is outlined in Priority 4, that says, "people with disability are supported to access assistive technology." ¹¹

Under the NDIS people are funded for low, medium, and high-cost Assistive Technology (AT) according to their needs.

A welcome change in the new Support.at. Home program is the separation of AT and Home Modifications from daily funding. People 65 and over now have access to a separate total of \$15,000 for Home Modifications and \$15,000 or above with a prescription for AT.

The processes for approving prescription AT must be well articulated to the My Aged Care funded services working at the coal face because prescription AT such as power wheelchairs and hospital grade beds can be significantly more than \$15,000. Already, AT is being routinely rejected as outlined in the case study 'Barry's Story'.

AT not only supports the individual but also saves on long term health costs. A 2020 Review of Assistive Technology Programs in Australia found that for every \$1 spent on assistive technology, there is a \$2 saving related to the potential cost of paid carers, support services, and medical services. An annual spend of \$16 billion dollars can save \$32 billion dollars. 12

SOLUTION 3: ensure training for all decision makers covering the importance of AT. Ensure that prescription items include a range of items that enable people to remain safely at home and prevent injury (such as appropriate wheelchairs and beds).

¹⁰ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

¹¹ Australia Disability Strategy 2021-2031 The Strategy and supporting documents | Disability Gateway

¹² Australian Healthcare Associates. Review of Assistive Technology Programs in Australia: Final Report and Supplementary Technical Report for the Australian Government Department of Health. Canberra: Department of Health. June 2020

Edward.is.a. Edward.is.a. Edward.is.supported.by.his.son.and. through.a. Home. Care. Package; Edward.tries.not.to.rely.too.much.on.his.son.who.has.a.young.family. and.a.full_time.job;. Edward.requires.a.power.wheelchair.to.access.the.community.independently? however.within.his. Home. Care. Package.he.does.not.have.sufficient.funds.to.upgrade.his.76_year_old. power.chair;. Edward.during.his.early.life.had.a.high.paid.executive.job;. Following.a.brief.break.for. rehabilitation.he.took.on.less.challenging.customer.service.work.and.maintained.a.steady.income. until.retirement.at. All.lis.accurate.to.say.that. Edward.has.been.a.contributor.all.his.life;. He.could.not. have.foreseen? nor.planned.for? the.quadriplegia.he.acquired.in.an.accident.96.years.ago;. Edward. now.remains.isolated.in.his.home.most.days? experiencing.depression.and.not.wanting.to.be.a. burden.on.the.community.he.once.actively.participated.in;

Disability Supports in Residential Aged Care

People in residential aged care with permanent and complex disability require a level of support often unavailable in aged care facilities.

People with complex disability in residential aged care require specialist bowel and pressure care to avoid complications associated with their disability that is not available in many residential aged care facilities, or where it is available, there is, in many cases, a lack of knowledge about disability. Consequently, people with disability are often either turned away from local and preferred facilities due to a lack of funding to enable sufficient nursing support or admitted but suffer medical complications such as pressure areas that can limit quality of life, or in severe cases, lead to hospitalisation and death.

In 2020, the average annualised support in residential aged care for those with high needs was approximately \$104,000 with a maximum capped amount (inclusive of personal contributions and government contributions) of \$139,000 a year.¹³ This compares to the average high level specialist disability accommodation NDIS funding of \$199,601 with the amount for the highest impairment category having an average of \$493,170 a year.¹⁴

The costs outlined above are indicative of the access and the amount of care provided. Clinicals in residential facilities, working within the existing funding model, do not have the capacity to adequately support people with complex disability. People in residential aged care are either

a. Turned away from multiple facilities due to their shifting discharge dates as well as the complexity (and cost) of their care needs. This blocks beds in hospitals as people wait for discharge and costing \$1200 per day.

¹³ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

¹⁴ ibid

b. Offered a place but need to constantly advocate for their care needs such as complex bowel care.

Access to appropriate and safe care is a minimum requirement for all people with disability in residential aged care. This includes intake assessments from occupational therapists trained in disability care and ongoing support from nursing and aged care employees also trained in disability care.

SOLUTION 5: Creation an incentive system for Residential Aged Care facilities to enable them to accommodate people with complex disability. This could be an additional level of funding or a complex disability supplement. The system must also be adapted to accommodate flexible discharge dates for people transferring from complex rehabilitation programs.

SOLUTION 6: Development of support mechanisms whereby Independent Assessors assisting people with complex physical disability and using the AN-ACC Assessment Tool have the option of speaking with clinical teams who specialise in support for a particular disability. For example, a registered nurse in a spinal unit.

SOLUTION 7: Mandated training for aged care nursing staff and other workers to understand the daily physical support needs of people with disability.

SOLUTION 8: Provision of needs assessed AT for people with disability in residential aged care to enable active participation.

Maxwell.is.a. war_old.man.who.had.a.fall.from.height.leading.to.a.high_level.SCI; At.the. time.of.his.accident?Maxwell.lived.alone.at.home.and.worked.in.a.professional.senior. management.role;.However?due.to.his.age?Maxwell.was.ineligible.for.NDIS.and.only.eligible.for.My.Aged.Care;.Maxwell's.Home.Care.Package.was.insufficient.to.support.his.care.needs? his.house.and.assistive.technology.would.have.been.funded.at.his.own.expense;.Despite.his. mental.acuity.Maxwells.only.discharge.option.was.to.a.residential.aged.care.facility?a. choice.Maxwell.would.not.have.had.to.make.were.it.not.for.his.accident;.

Maxwells.care.needs?include.a.complex.assisted.manual.bowel.routine?hoist.transfer? assistance.with.all.personal.care.and.activities.of.daily.living?regular.chest.physio.and. manual.cough.assist;.Maxwell.remained.in.hospital.for.7@months.because.he.was. declined.a.place.in.over.776.aged.care.facilities.due.to.his.high.clinical.care.needs

Urgent Change is Required

People 65 and over who have already had their retirement plans shattered by an acquired complex and permanent disability have been continuously overlooked by repeated reforms and inquiries. The two-tier system we have created is a form of age discrimination and should be immediately addressed by implementation of the above actions.

Contact:

SCIA Policy and Advocacy Team, representative@scia.org.au

Appendix A, Additional Case Studies

Barry's Story

Barry?a. 66_year_old.quadriplegic.who.lives.alone.has.found.that.when.he.is.unable.to.get.the. support.he.needs.when.l.signed.up?l.was.told.that.if.l.needed.something.and.l.saved.up.for.it?l. could.have.iti.That.worked.for.about.9_0.years.but.recently.nothing.is.approvedi.My.OT. suggested.l.ask.for.a.Thermomix.because.l.am.finding.it.hard.to.cook.but.it.was.rejectedi.l.don't. know.whyi.

Grayson's Story

Grayson?an. 66_year_old.who.is.finding.it.hard.to.remain.at.home?is.looking.for.a.suitable.aged. care.facility;.He.has.visited.several.in.his.local.area?but.his.power.chair.does.not.fit.in.the. bathroom;.Grayson.feels.trapped?unable.to.remain.at.home.and.unable.to.find.a.suitable.aged. care.facility.to.meet.his.needs;.As.Grayson.explains.»If.I.go.to.the.spinal.ward.they.know.how.to. look.after.me;.They.can.get.me.a.special.bed;.If.I.go.to.my.local.hospital.through.general. admissions?they.don"t.know.about.SCI;.The.same.goes.for.nursing.homes?they.won"t.know.how. to.treat.me;.If.there.was.a.spinal.aged.care.facility?I.would.sign.up.tomorrow.;

Phillip's Story

Phillip.acquired.a.SCI.from.a.medical.procedurej.The.Pj26366.Home.Care.Package.did.not.cover. the.necessary.home.modifications?nor.the.Pj7863666.required.for.his.care.annuallyj.Phillip.was. fit.and.healthy.at.the.time.of.his.accident.but.at.232.was.two.years.too.old.to.access.the..NDISj. Ultimately.after.receiving.informal.care.from.his.wife?Phillip.moved.into.the.only.accessible.and. available.aged.care.facility?over.an.hour's.drive.away.from.his.wife.and.familyj.Phillip.says.vl.just. don't.feel.that.because.l.am.over.21my.life.is.worth.less.than.someone.who.is.86j.l.feel.like.l.am. in.prison.in.the.aged.care.facilityj.Everyone.around.me.has.age.related.issues.and.l.have.only.a. physical.disability._but.l.am.unable.to.do.anythingj.l.want.to.be.with.my.family.and.my.dogjk

Christine (Phillip's Wife's) Story

Because.Phillip.was.in.a.wheelchair?he.could.not.access.the.family.homei.However? paradoxically?to.have.the.Home.Care.Package.assessment.that.would.fund.home. modifications?Phillip.was.required.to.be.at.homei.Christine?at.her.own.expense?modified.the. house.to.bring.her.husband.home.for.the.assessmenti.Unfortunately?the.P@67666.did.not.cover. Phillip's.care.requirements.and.Christine.trained.herself.to.be.an.informal.carer?helping.Phillip. with.his.complex.care.needs?including.toileting.and.transferringi.Two.years.after.the.accident. and.after.much.stress?Christine.had.a.heart.attack.and.could.not.carry.out.her.role.as.a.careri. Phillip.moved.into.respite?and.later.an.aged.care.facilityi.Now?if.Christine.wants.to.see.her. husband?it.requires.a.8_hour.round.tripi.lf.he.wants.to.come.home.to.see.his.family?it.becomes. a.0_hour.trip.for.Christinei.lt.is.likely.that.the.outcome.would.have.been.considerably.different. for.this.family.if.the.accident.had.occurred.when.Phillip.was.eligible.for.NDIS.support;

Iris's Story

Iris.has.paraplegia.(acquired.over.the.age.of. 20)?her.husband.has.Alzheimer's.disease;.Iris. manages.their.Support.at.Home.packages;.Iris.says?»I.am.FURIOUS.about.the.way.my. government.is.treating.me?expecting.me.to.spend.my.life.savings.on.transport?equipment? physio?etc;.I.received.no.home.modifications.apart.from.two.ramps.and.a.shower.hose;.Not.one. sink.has.been.made.accessible;

Iris.also.discusses.the.supports.her.friends.in.the.NDIS.receive?such.as.auto_opening.curtains. and.custom.wheelchair.cushions?which.she.believes.would.significantly.help.her.with.daily. activities;.Iris.raises.another.critical.issue.saying.when.she.searches.online.for.assistive. technology.and.mentions.that.her.funding.is.through.My.Aged.Care?the.suppliers.will.not.reply;. Iris.would.like.to.see.the.tighter.controls.in.the.NDIS.so.that.funds.can.be.spent.on.those.over. 41. She.explains. Currently?I.feel.overwhelmed.most.of.the.timer

Roger's Story

Roger.developed.Parkinsons.in.his. 66's;.He.lived.comfortably.at.home.until.a.fall.caused.a.spinal. injury?leaving.him.in.excruciating.pain.and.leading.him.to.a.decision.to.move.to.residential.aged. care;.The.aged.care.facility.Roger.moved.to.had.inadequate.disability.supports;.Roger.was.not. assessed.by.an.Occupational.Therapist.for.suitable.equipment.such.as.a.tailored.cushion.for. sitting?a.wheelchair.or.an.air.mattress;.Roger.spent.almost.all.the.daytime.in.his.room?in.pain. and.seated.in.a.standard.chair;.Within.six.months.Roger.had.developed.pressure.sores.on.his. back?his.buttocks?and.his.lower.spine.which.remained.untreated.for.some.time.and.ultimately. caused.a.severe.infection?nearly.costing.Roger.his.life;.