



PLANNING FOR TRANSPORT IN SELF-DIRECTED CARE

NATIONAL DEMENTIA HELPLINE

1800 100 500

The National Dementia Helpline is a Government initiative

FIGHTDEMENTIA.ORG.AU/NSW

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

Alzheimer's Australia NSW ABN: 27 109 607 472 June 2015

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

INTRODUCTION

Government funding for both home care and disability packages has moved towards person centred planning, or self-directed care. This approach is also called consumer directed care (CDC).

The aim of self-directed care is that people receiving government funding have more choice and control over the services they receive, whether they are living in the community or in residential care. Having more say in how funds are spent means people with dementia and their carers should get services and supports that make their lives easier.

Self-directed care is available under home care packages, funded by the Federal Government, and the NDIS and the State Government program, *Living Life My Way*. Information and assistance are available under these programs to help guide people when planning their services.

Home Care Packages

An Aged Care Assessment Team (ACAT) will determine the home care package the person with dementia is eligible for and will refer them to home care service providers in the

area. A list of providers can be found at www.myagedcare.gov.au. If the providers have appropriate packages on offer, the person with dementia can decide which provider best meets their needs and value for money. The provider will have an adviser or case manager to work with and help the person get the support they need, the way they want it.

Depending on their eligibility, some people on aged care packages can access additional services to those provided by an aged care provider by contacting the service, such as community transport, directly.

NDIS

People with dementia who are eligible for NDIS funded supports have access to a planner who will help the person decide how they would like to manage that funding. There are a number of management options available, including self managing the funding, nominating another person or the National Disability Insurance Agency to manage the funding and using a registered plan management provider.

Living Life My Way

Living Life My Way has created a service, Ability Links NSW. The service can provide coordinators to help people who receive funding from the NSW Government to use the disability service system.

Planning for transport

However, even with assistance from planners, many people do not make sufficient consideration for transport requirements. While some organisations, particularly some daycare centres, provide transport for clients, there is a widespread tendency to assume that someone else is responsible for making transport arrangements.

This can be a daily stress, affecting the person concerned and the carers who tend to carry the main burden for meeting transport needs. People with dementia who live alone are particularly disadvantaged in identifying and accessing transport.



This brochure is intended to help people with dementia, their carers and advisors to identify and allow for the transport needs of a person with dementia when planning the support and services they need to live in the community.

Unfortunately, even with planning it is not always possible to meet these transport needs. Under NDIS clients are allocated a transport allowance which cannot be increased. Providers who deliver aged care packages may not be able to ensure the funds cover transport. However while there are funding limitations, it is important to plan as much as possible for transport.

THE IMPORTANCE OF TRANSPORT

Access to appropriate transport is very important to people with dementia living at home. The Australian Institute of Health and Welfare estimates that 80% of people living with dementia in the community need assistance with private transport. The impact of the unmet need for transport is frustration and social isolation.



The impact of dementia on access to transport

The symptoms of dementia which may make it difficult for people to access suitable transport include:

- memory loss
- difficulty performing tasks such as organising transport
- problems with language
- being confused about time or where they are
- poor or decreased judgment
- misplacing things
- changes in mood or behaviour which may involve behaving inappropriately while travelling
- difficulty in coping with changes to arrangements.

In addition to these difficulties, people with dementia, carers, families, friends and health professionals often find it difficult to locate and interpret transport information.

The first step in ensuring that transport is included in the planning process is to assess the person with dementia's transport needs.

ESTABLISHING THE PERSON'S NEED FOR TRANSPORT

When considering services and supports a person with dementia may need to access it is important to consider:

- the activities that the person with dementia wishes to participate in such as
 - shopping
 - hobbies
 - seeing family and friends
 - day care
 - appointments with doctors and other health professionals
 - other appointments such as the hairdresser
 - group activities such as church, support groups, men's shed
 - getting out of the house
- current living and transport needs
 - existing transport arrangements, including those provided by organisations such as day care
 - the activities that are difficult for the person to access
 - support available from friends and family in providing transport
 - transport options that would make it easier for friends and family to support the person with dementia

- future needs
 - dementia symptoms change over time and these changes may mean that transport arrangements will need to change. For instance, if the person is currently driving, consideration needs to be given to how they will they get about when they give up their license
 - if the person has a carer or assistance from friends and family, the future role of these people needs to be considered.

It is a good idea to draw up a list of the person's transport needs and current transport options. This will help to identify the gaps in current and future transport provision.

Friends and family can play a key part in meeting the transport needs of a person with dementia but it is a good idea to discuss their roles when developing a self-directed care plan, rather than assume they can meet the person's transport needs or that existing arrangements are sustainable.

Many people with dementia live alone and may find it particularly challenging to organise their transport.

The next step is to look at how the transport gaps can be filled.

TRANSPORT OPTIONS

The transport needs of people with dementia vary with the stage and type of dementia, individual responses and other medical conditions they may have.

Individuals in the early stages of dementia are generally capable of maintaining their regular activities for a limited period. Many continue to drive and are capable of using public transport for some time.

In later stages of dementia most people need assistance to identify and organise appropriate transport. Many need to travel with an escort.

The main transport options for people with dementia are outlined below.

Driving or being driven

Some people with dementia can continue to drive however everyone who has dementia has to give up driving at some stage. When making plans it is important to acknowledge and allow for this fact.

People with dementia who live with a carer often rely on the carer to drive them, although carers may be working and have other responsibilities. Furthermore, many carers have their own health issues,

they may not drive or be confident drivers or the person with dementia may be a difficult passenger.

For tips on travelling with a person with dementia as a passenger see *Staying On The Move With Dementia* at www.fightdementia.org.au

Some day care and respite services provide collect and drop off transport for people attending the centres.

There are also private transport services that provide transport for people with health issues, including people with dementia. Health professionals, your local council or a search of the yellow pages may direct you to providers who service your area.

Australian Disability Parking Schemed (ADPS)

Driving a person with dementia can be easier if they are eligible for the ADPS; the national scheme for disability parking permits which helps eligible people park nearer to their destination. The scheme is progressively being rolled out in States and Territories. For information on the Mobility Parking Scheme in NSW, phone Roads and Maritime

Services (RMS) on **132 213** or go to www.rms.nsw.gov.au/usingroads/mobilityparking

Public transport

Many people in the earlier stages of dementia, especially those who have used public transport regularly prior to the diagnosis, can continue to use public transport for some time, particularly on familiar routes. People with more advanced dementia symptoms may need to be accompanied on public transport.

Information on routes, timetables and accessibility for NSW public transport can be found at www.transportnsw.info, by **phone: 131 500** and **TTY: 1800 637 500**.

A trip planning facility for accessible services is available.

Companion Card

The Companion Card allows people with a severe and profound disability, who require attendant care at events and venues, to participate without having to pay for a second ticket for their attendant. The Companion Card is recognised on most public transport.



For more information in NSW call **1800 893 044** during business hours or visit www.nswcompanioncard.org.au.

Community transport

Community transport operators (CTOs) provide transport for the frail aged, the disabled and the transport disadvantaged. The providers reflect the needs and resources of the area they serve. Thus each is slightly different.

Because CTOs operate differently, not all providers offer the full range of benefits but the features offered by the service can include:

- door to door, or even door through door, service
- service on request
- volunteer escorts
- rides to a variety of destinations, including shopping, medical and social outings
- assistance for disabled passengers
- low or little cost
- many drivers and escorts, both volunteer and paid, are accustomed to dealing with vulnerable passengers.

Eligibility criteria and fees charged by community transport vary.



Current providers of community transport include community organisations, local councils and members of the National Aboriginal and Torres Strait Islander Community Transport Network.

The Community Transport Organisation is the peak body for community transport providers in NSW. Its website, www.cto.org.au provides a directory of community transport providers in NSW and the ACT. The website includes a search function to locate nearby services.

The Regional Transport Coordination Program may assist people who live outside metropolitan Sydney and experience transport disadvantage to access services.

The contact list for the regional transport coordinators can be found at: www.transport.nsw.gov.au/content/regional-transport-coordinators

Taxis

Taxis are usually more expensive than other forms of public transport but they provide door to door service and some people with dementia find them easy to use. Taxis can be particularly useful for people with dementia if they develop a trusting relationship with a regular driver.

The cost of using taxis can be partly alleviated by the Taxi Transport Subsidy Scheme (TTSS) which provides subsidised travel. The TTSS is available to people who are unable to travel on public transport without the constant assistance of another person.

In NSW further information can be obtained by calling TTSS on **1800 623 724** (toll free) or from www.transport.nsw.gov.au/ttss.

Walking

Walking can have a positive impact on the wellbeing, self-esteem and physical health of people with dementia. However, dementia can impact on a person's ability to navigate and recall common routes.

FINDING INFORMATION

Identifying available transport options can be challenging. The following contact points are good starting points, however people with dementia and carers may need to ask for help in navigating the various sources of transport information.

- For assistance with public transport trip planning, timetables, ticketing and travel information, including how to find assistance see **www.transportnsw.info**, phone **131500** and **TTY 1800 637 500**.
- For information on community transport in your area see **www.transportnsw.info** and search for “community transport” to find service providers across NSW **www.transport.nsw.gov.au/content/community-transport-contact-list** or **www.cto.org.au/ct-providers**.
- Information on the **Taxi Transport Subsidy Scheme** can be found at **www.transport.nsw.gov.au/ttss** phone **1800 623 724**

- The local council may be able to provide information on community transport and other transport providers in your area. **The Local Government NSW** site has links to local councils in NSW **www.lgnsw.org.au/about-us/council-links**

Other helpful resources include:

- **The Alzheimer’s Australia National Dementia Helpline** phone **1800 100500**. Alzheimer’s Australia also provides help sheets and a booklet called *Staying On The Move With Dementia* that addresses issues raised by driving and dementia. The website is **www.fightdementia.org.au**
- **CarersNSW** provide information, advice and support for carers on a number of issues, including self-directed care. The website is **www.carersnsw.org.au** or phone **1800 242 636**
- **My Aged Care** is a website and contact centre established by the Federal Government to help people navigate the aged care system, **www.myagedcare.gov.au** or phone **1800 200 422**
- **The National Disability Insurance Scheme** website has a page with information on participant transport funding, **www.ndis.gov.au** or phone **1800 800 110**



- **Ability Inc.** provides advocacy, information and training to enable people with disability to promote and exercise their rights and to understand their responsibilities. **www.abilityincorporated.org.au**
- **COTA** has developed *Home Care Today* which provides information and resources to help people understand how home care packages work using a consumer directed care approach. **www.homecareday.org.au**
- For language assistance phone the **Telephone Interpreter Service** on **131450**

This booklet has been prepared with funding provided by Ageing, Disability and Home Care (ADHC) in the NSW Department of Family and Community Services.