Tailor Made
One size does not fit all
A living well resource kit for people with younger onset dementia and their families.
ACH Group believes that growing older is a journey, not a destination. We think of it as turning a new page. We are here to listen to what is important to you, so that we can help you navigate the range of opportunities available. We offer advice, and support you to choose the life you want to live, where you want to live it.

Founded in 1952, ACH Group is a proud not-for-profit organisation. Our range of services help to maintain your independence, support you to be as healthy as you can be, and offer opportunities to maintain current social interests, or foster new ones.

We can support you to live independently in your current home, or if you are looking for a more manageable lifestyle, we have a range of Retirement Living options available to suit your needs.

For a more secure and safe environment, our Healthy Ageing approach within our Residential Care homes supports you to continue to live well.

ACH Group’s 1700 specialist staff and hundreds of volunteers share the belief that you should be valued and respected, connected to your community and in control of your life.

This mindset drives our every action to put you in control, to support you to lead a good life and continue to make a contribution to family, community and society.

Our staff celebrate diversity and welcome everyone as an individual, acknowledging sexual orientation and gender identity, respecting cultural backgrounds, religious and spiritual beliefs and practices.

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How to use the resource kit

The Tailor Made resource kit is a practical guide with information and guidance on how to access support to live well. Whether you need information or more formal support, services are available: you just need to know how to access them.

The resource kit seeks to support you to live your life your way, to identify what you need, find support and design a service that meets your needs and preferences.

The resource kit is divided with different tabs, each tab providing information on the principles of Tailor Made as well as practical tips and tools. You can read the kit from beginning to end, or go to specific tabs depending on the information you need at the time.

While the Tailor Made kit is developed for you, when accessing support from a service, it is important that you and the service work in partnership.

This kit is available as an online flipbook at achgroup.org.au

What is Tailor Made?

Tailor Made is a model of ‘living well’ specifically developed with and for people diagnosed with dementia or cognitive impairment under the age of 65, and their family members.

The needs of younger people with dementia or cognitive impairment and their families are complex and different to those of different generations.

Tailor Made brings together consumers and service providers to co-design a new way of offering support services that supports people to continue living with meaning and purpose. Tailor Made seeks to challenge the way that traditional support can be provided, to remain physically active, mentally stimulated and socially connected in ways that are tailored to a person’s abilities and interests. There is still a lot of living to do and you can be supported to do it your way!

*Anyone in close association with the person with dementia can be regarded as a ‘family member’ regardless of whether or not they are related.
Support services or respite care is about ‘living well’

There are many misconceptions about support services or what ‘respite care’ is. While respite care is a service, we believe that a sense of wellbeing from a service should also be the outcome – to ‘live well’. Research tells us that it is possible to live well beyond the diagnosis of dementia.

Support services don’t have to be one size fits all and can be customised to fit your lifestyle and provided in various ways.

Support can be:

- Information and assistance to find what your options might be either early in your diagnosis or at any stage of the condition.
- Continuing to do the things you did before diagnosis - flexible support to allow you to keep doing the things you used to do.
- Accessing services to maintain your independence and existing abilities and strengths.
- Informal support, where a friend or family member can provide their time and support.
- Services provided by organisations who offer a range of support options.
**What are the benefits?**

Support services can benefit the person with dementia as well as their family members. A person with dementia can be supported to continue or take up new interests and relationships, family members can take up the option to have some time to themselves to pursue their own interests or to get some rest.

Support can be accessed every now and then or on a regular basis, for a few hours to a few weeks.

Support can:
- Provide enjoyment and pleasure through social activities.
- Keep you in touch with friends and the local community.
- Help maintain and grow skills, abilities and independence.
- Increase confidence and wellbeing.
- Provide more control in your life.
- Reduce boredom or depression.

To access further information and support - see Useful Contacts on pg. 26

**When might you need support?**

Changes to relationships and lifestyle can be challenging. Taking up the option of help can be hard but trying out services early often helps maintain health and wellbeing. While there is no right or wrong time to access support, building a relationship with a service may make it easier in the future.

Accessing social support to keep engaged in the community can be a good place to start.

If you are not working or do not drive, services can provide opportunities to socialise, go to the gym, get to appointments and continue to do things you like or have always wanted to do.

When you need more support, community, day and overnight respite are other options that are available.

### Accessing social activities with additional support, learning, creative or sporting activities:
- Golf
- Walking
- Fishing
- Computing
- Art and photography
- Singing in a choir
- Going to the football

Good for you and good for your family.

### Accessing support in your home when you need more focused or one to one care:
- Support with housework
- Support with meal preparation
- Support with garden and home maintenance
- Support with transport
- Support for personal care needs
- Support to organise paperwork or photos

To free up quality time together.
How can Tailor Made services be provided?

4 Steps to support you to 'live well'

If you are wanting to review a support service before trying it or if you have decided that you may need more support, the Tailor Made model explains how you can find the information you need, how services can be tailored and focuses on quality support.

The Tailor Made model is made up of four key steps, each supported by practical strategies that make it achievable to implement the approach. A support checklist reinforces each step.

**M**ap
Help me to understand my support choices to stay in control.

**A**ssess
Support me to clearly state my and my families needs so they can be understood.

**D**esign
Design services with me that are flexible and responsive to my and my families needs and focus on my wellbeing and quality of life.

**E**xperience
Provide services for me that are age, gender and culturally appropriate, engage me in the community and enhance my sense of purpose and belonging.
A service should respond flexibly to your goals, aspirations and plans. Whether provided in your own home, in the community through social activities or outings or centre based or residential environments, the focus of the service should be all about you, your life, health and wellbeing. Providers need to listen and deliver services that are flexible and consider your needs and abilities, the physical environment, local services, access to transport, flexible hours (including weekends), safety and the right support staff.

Services need to prioritise your wellbeing, likes, dislikes and wants and not be about ‘filling time’ or fitting in with an existing menu of options that don’t fulfil or engage you. Every opportunity to engage in the community and to develop appropriate activities that appeal to your age, background and interests should be taken.

Everyone’s story and needs are different. Your needs should be heard and understood. You can ask for services that fit with your own values and lifestyle and ask for appropriate activities that appeal to your age, background and interests. Services need to treat you as unique, take the time to get to know your story, your background, your likes and dislikes and your cultural and language needs. Services need to provide ongoing opportunities to listen to your needs, review your options and provide care that is flexible enough to adjust with life changes.
Support checklist

How to help plan and review services to meet your needs

This support checklist can be used to help with planning how to access a service or to review the ‘fit’ of a service that you may already be using.

The aim of the checklist is to assist you to make decisions about the support you need. The questions have been designed as prompts to help with this decision making. Read each question and provide the best response.

It can help you work out what further information you need, what you want from a service and how to ask for it.

To access further information and support - see Useful Contacts on pg. 26

MORE
**MAP your options for support**

The following checklist can be used to help with assessing your individual support needs, the type of service you want or to review the fit of a service that you may already be using.

<table>
<thead>
<tr>
<th>Help me to understand my support choices to stay in control.</th>
<th>YES</th>
<th>PARTLY</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand the benefits that support can give to me</td>
<td></td>
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<tr>
<td>I understand the timing of support and when I can access it</td>
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<tr>
<td>I understand the types of respite and supports that are available</td>
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<tr>
<td>I understand what government and private funded services I am eligible for</td>
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<tr>
<td>I understand what services I can access in my local area</td>
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<tr>
<td>I have help to or feel supported to navigate the service system</td>
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<tr>
<td>I understand the pathways and processes involved in accessing support</td>
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<tr>
<td>I feel informed enough to make a decision about accessing a service</td>
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<tr>
<td>I feel in control of my choices</td>
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<tr>
<td>I have had the opportunity to visit a service, program or activity</td>
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<tr>
<td>I know where to go if I need more help</td>
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</table>

**If no, what action is needed?**

Eg. You can speak to a service advisory or Alzheimers Australia SA younger onset dementia key worker.
**ASSESS and identify what you need**

The following checklist can be used to help with assessing your individual support needs, the type of service you want or to review whether a service you are already using is appropriate.

<table>
<thead>
<tr>
<th>The organisation gives me the opportunity to explain my situation and express what I need</th>
<th>YES</th>
<th>PARTLY</th>
<th>NO</th>
<th>If no, what action is needed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The organisation takes the time to get to know me and what is important to me</td>
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<tr>
<td>The organisation acknowledges and respects my cultural needs including assistance with language, spiritual needs or food customs</td>
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<tr>
<td>I feel that I have developed a good relationship with my organisation</td>
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<tr>
<td>I feel involved in the decisions about my support</td>
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<tr>
<td>The organisation tries to understand my needs and works to tailor a service to meet my needs</td>
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<tr>
<td>I have confidence and trust in the organisation to provide the service I need</td>
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<tr>
<td>I have the opportunity to provide feedback and discuss other support options if my circumstances change</td>
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<tr>
<td>I am able to ask for changes to the service that is provided</td>
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</tbody>
</table>

The following checklist can be used to help with assessing your individual support needs, the type of service you want or to review whether a service you are already using is appropriate.

_Eg. You can speak to a service provider about your needs or to review the service you may already be using._
**DESIGN and tailor the support you need**

The following checklist can be used to help with assessing your individual support needs, the type of service you want, or to review the fit of a service that you may already be using.

<table>
<thead>
<tr>
<th>Design services with me that are flexible and responsive to my and my families needs and focus on my wellbeing and quality of life.</th>
<th>YES</th>
<th>PARTLY</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>The organisation is adaptable, it listens to my needs and tries to tailor the service to meet my needs</td>
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<tr>
<td>The organisation has younger onset dementia specific services</td>
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<tr>
<td>The organisation involves me in the design and planning of the service</td>
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<tr>
<td>The organisation provides a range of formats that suit me; one to one or groups, in-home or in the community</td>
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<tr>
<td>The organisation provides opening hours, days and times that suit me</td>
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<td></td>
<td></td>
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<tr>
<td>The organisation is available in my local area and provides transport</td>
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<tr>
<td>The physical environment meets my needs</td>
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<tr>
<td>The organisation adapts what is provided as my needs change</td>
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<tr>
<td>The organisation has staff that are trained in supporting younger people with dementia and provides consistency</td>
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<tr>
<td>The service tries to match the staff member/s to my interests and abilities</td>
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<tr>
<td>The service gives me a sense of freedom and independence</td>
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</table>

If no, what action is needed?
Eg. You can speak to a service provider about your needs or to review the service you may already be using.
EXPERIENCE the support you want

The following checklist can be used to help with assessing your individual support needs, the type of service you want, or to review the fit of a service that you may already be using.

<table>
<thead>
<tr>
<th>Provide services for me that are age, gender and culturally appropriate, engage me in the community and enhance my sense of purpose and belonging.</th>
<th>YES</th>
<th>PARTLY</th>
<th>NO</th>
<th>If no, what action is needed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have the opportunity to interact with people my own age and gender</td>
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<tr>
<td>I am supported to develop new friendships</td>
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<tr>
<td>I have the opportunity to do things for myself</td>
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<tr>
<td>I have the opportunity to learn something new</td>
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<tr>
<td>I have the opportunity to be out in the community</td>
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<tr>
<td>I have the opportunity to do activities that match my level of fitness; gentle walking or cycling</td>
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<tr>
<td>The organisation supports me to tailor activities that suit my own interests</td>
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<tr>
<td>The organisation supports me to do activities I have always wanted to do or maintain an existing skill or hobby</td>
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<tr>
<td>The organisation provides services that meet my cultural needs</td>
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<tr>
<td>The organisation supports me to continue to keep in touch with friends and family</td>
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<tr>
<td>The activities give me a sense of purpose and belonging</td>
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</table>

How can Tailor Made services be provided?
What do you need to live well with younger onset dementia?

While the Tailor Made Project and the living well approach focuses on service access and development, there is much more to living well with a diagnosis of dementia that involves the individual and the wider community.

People living with dementia, their families and supports have told us loud and clear what is important to them.

If you would like more information about Tailor Made and how we can support you to live well, please contact the Dementia Advisory Service through the Dementia Learning and Development Unit, ACH Group on 1300 22 44 77.
Useful Contacts

For Information and Support

Alzheimer’s Australia - National Dementia Helpline
A telephone information and support service for people with dementia, their carers, families and friends, as well as people concerned about memory loss. Users who are deaf or have a hearing or speech impairment can phone the National Relay Service on 13 26 77.
Tel: 1800 100 500

Alzheimer’s Australia - Living with Memory Loss Program
A FREE 5 week program for people with early stage dementia and their family members. Information and support is provided in a small group setting, to learn from and share with others in a similar situation and an ongoing support group is available.
Tel: (08) 8372 2100

Alzheimer’s Australia SA – YOD (Younger onset dementia) Key Worker Program
A first point of contact for people with younger onset dementia, their families and carers which provides information, support, counselling, advice and helps people to engage with services that are appropriate to their individual needs.
People must be under the age of 65 when first contacting the service or entering the program; already diagnosed with younger onset dementia [all forms of], or a person with symptoms of dementia that have not yet been diagnosed. People with Mild Cognitive Impairment are also eligible for the Program.
Tel: 1800 100 500
Website: fightdementia.org.au/national/support-and-services/services-and-programs/national-younger-onset-dementia-key-worker-program

Alzheimer’s Australia – ATSI Specific
A range of Aboriginal and Torres Strait Islander specific dementia help sheets are available.
Website: fightdementia.org.au/about-dementia/resources/aboriginal-and-torres-strait-islander

Alzheimer’s Australia SA – Connexus Program
A social support program which aims to reduce social isolation and improve quality of life through a variety of flexible social opportunities.
The program includes: monthly support group and outings, a weekly day program in partnership with the City of Onkaparinga at Elizabeth House (Southern Adelaide) and a weekend retreat for people with dementia and family members.
Tel: 1800 100 500

Creative Ways to Care Program – Carers SA
Developed to empower family and friends caring for someone with dementia to gain knowledge, skills, resources and confidence in caring for someone at home.
Tel: 1800 242 636
Website: carers-sa.asn.au/news-events/events/creative-ways-to-care

Carer and Disability Link (Adelaide Hills)
A unique community-based organisation supporting family carers across the Adelaide Hills and Alexandrina area, providing direct services to people, including a monthly younger onset dementia support group (Mount Barker) and monthly younger onset dementia support group for carers and family members (Strathalbyn).
Tel: (08) 8389 7383 (Woodside)
Tel: (08) 8549 1299 (Strathalbyn)
Website: carerwellness.org.au/activities/
It’s Your Life Program - Carer Support & Uniting Care Wesley Bowden
A dementia specific program which provides support groups and other events and social activities for carers of people with younger onset dementia.
Tel: (08) 8206 0777

Northern Carers Network
Support to carers living in Adelaide’s Northern region, providing assistance to people caring for a friend or family member in the home environment. Carers are supported in their caring role, through counselling, information, support, advocacy, respite and linking to appropriate services in their local community.
Tel: (08) 8284 0388
Website: ncnw.org.au
Email: office@ncnw.org.au

Team TLC - Tender Loving Carers
A fundraising group under the Alzheimer’s SA umbrella which raises funds to support the carers of people living with younger onset dementia including ‘Wellbeing Days,’ which offer relaxation, workshops, support, counselling and massage. Respite retreats also support carers and the person living with dementia to go away together.
Email: teamtlc@outlook.com

Transport Services
Transport Services can be accessed through:
- Commonwealth government services (if over 65)
- State, territory or local government health or transport departments
- Local councils
- Not-for-profit community transport providers (e.g. aged care providers like ACH Group or the Red Cross),

Companion Card & Plus One Free Companion Card
The Companion Card is a card issued for people who require attendant care support, which allows a companion to enter free of charge to participating venues and activities.
Tel: 1800 667 110
Website: sa.companioncard.asn.au
Email: companion.card@sa.gov.au

South Australian Transport Subsidy Scheme (SATSS)
People with permanent disabilities can apply for either the Plus One free Companion Card or the Companion Card. Holders are able to travel on all Adelaide Metro bus, train and tram services throughout metropolitan Adelaide accompanied by a carer. While the Plus One Free Companion Card holder must be in possession of a valid Metrocard, single or day trip ticket and concession card (if applicable), the companion/carer can travel free of charge.
The cards have different eligibility criteria and application processes.
State and Commonwealth Subsidised Programs:

There are a small number of funding streams available to people aged under 65 years with an aged related permanent disability such as dementia, or under the age of 50 for Aboriginal and Torres Strait Islander people. Funding responsibility sits with the States and Territories and with the National Disability Insurance Scheme (NDIS), however not all types of dementia are recognised as eligible for Disability SA funded services. The majority of services for people with younger onset dementia are funded through the aged care sector. Disability SA funding will cease from June 2018 and the NDIS will be accessible for adults (18-64 years) from July 2017. (See Using Services on pg. 32)

Private Services – Fee for Service

If you are not eligible for some of the State or Commonwealth Programs you can pay privately for a service through a ‘fee for service’ arrangement (see the Carers Gateway link in Using Services on pg. 32)

South Australian Home and Community Care (SA HACC) Program

The main source of funding available for people under 65 is through the SA HACC. Services available include: social support, transport, respite care, domestic assistance and personal care. Not all aged care providers are funded for SA HACC. Other non-government organisations, councils and Domiciliary Care SA provide some funding for people under 65 years with cognitive impairment or dementia (See Useful Contacts on pg. 26).

National Disability Insurance Scheme (NDIS)

The NDIS is a new way to help people under 65 years with a disability. The NDIS helps families and carers with funding and information about services to support people. The NDIS is being introduced in stages and from July 2017, adults aged 18 to 64 years of age will begin to enter the NDIS based on where they live.

Tel: 1800 800 110
Website: ndis.gov.au

Commonwealth Carelink and Respite Centres (CCRC)

Short term emergency residential and in-home respite and non-emergency occasional respite is funded through the CCRC. For residential emergency respite, you will require an ACAT referral. The CCRC can support you to find facilities with vacancies. For in home emergency respite, they coordinate brokerage for care with an agency.

Tel: 1800 052 222

Useful Contacts
Using Services

ACH Group - Tailor Made Project
Younger onset dementia specific information, resources and services provided in a more tailored way based on individual needs.
Tel: 1300 22 44 77
Website: achgroup.org.au/tailor-Made

ACAT – Aged Care Access Team
To receive respite care in a residential care home or for emergency respite care you will require an Aged Care Access Team assessment and approval to receive government-subsidised aged care services. ACAT referrals are organised through the My Aged Care website.
Tel: 1800 200 422
Website: myagedcare.gov.au

Aged Care Providers and Carers Gateway
ACH Group is one of the organisations that can support you in your care. Funding availability and eligibility varies from organisation to organisation. A full list of providers in your local area can be searched on the Carers Gateway.
Tel: 1800 422 737
Website: carergateway.gov.au

Carer Gateway
Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services in their area.
Tel: 1800 422 737
Website: carergateway.gov.au

Carer Support
Respite and support services are available for carers in metropolitan Adelaide:
- Carer Support Campbelltown Centre
  Respite FREECALL 1800 052 222 including emergency respite
  Tel: (08) 8206 0777
- Carer Support Glandore Centre
  Tel: (08) 8379 5777
General enquiries email: enquiries@carersupport.org.au

Councils in your local area
Some councils are funded to provide services for people under 65 in their local area including social support programs, and home help. Check with your council to see what is available. A list of council websites is available through the Local Government Association [LGA].
Website: lga.sa.gov.au

Disability SA & Disability Services
Contact the Disability Information and Referral Service for general enquiries and information about disability services and support in South Australia.
Tel: 1300 786 117 [9.00 am to 5.00 pm]
Website: dcsi.sa.gov.au
Email: disabilityinfo@sa.gov.au

Domiciliary Care - Department for Communities and Social Inclusion (DCSI)
Respite, domestic and social support are available through Domiciliary Care. Aboriginal and Torres Strait islander people under 50 years and people under 65 years with chronic conditions and who are not eligible for Disability Services may also qualify for services.
Tel: 1300 295 673
Website: sa.gov.au/topics/community-support/in-home-care/domiciliary-care
Aboriginal and Torres Strait Islander (ATSI) Specific

Aboriginal Elders and Community Care SA
A non-profit incorporated community based organisation that supports a continuum of aged care services to Aboriginal clients throughout metropolitan Adelaide.

Aboriginal Elders Village
Provides live-in facilities for up to 32 Elders with high and low care needs, as well as respite when required.

2 Oldford Street, Davoren Park, SA 5113
Tel: (08) 8287 1454
Fax: (08) 8287 1580
Email: eldersvillage@aboriginalccsa.org.au
Website: aboriginalccsa.org.au/

Aboriginal Home care
There are a range of services that can be accessed through the Commonwealth Home Support Program and Commonwealth Government Home Care Packages.

Level 1, 65 Henley Beach Road, Mile End SA 5031
Tel: (08) 8346 9155
Email: homecare@aboriginalccsa.org.au
Website: aboriginalccsa.org.au

A guide to accessing services can be found at:
Tel: 8346 9155
Website: aboriginalccsa.org.au/home-care-how-to-get-services
Email: homecare@aboriginalccsa.org.au

Culturally and Linguistically Diverse (CALD) Specific Services

Multicultural Aged Care (MAC)
Provides social support programs, education and training for CALD communities in South Australia.
Tel: 8241 9900
Website: macsa.org.au
Email: macsa@mac.org.au

Vietnamese Community in Australia/SA Chapter (VCASA)
The organisation offers specialised services for the Vietnamese community.
Tel: 8447 8821
Website: sa.vnca.org.au/

Multicultural Communities Council of SA (MCCSA)
The peak organisation that services, empowers and advocates for cultural and linguistically diverse (CALD) communities in South Australia.
Tel: (08) 8346 9155
Website: mccsa.org.au/
We would like to extend our thanks to the Tailor Made Reference Group for their keen insights and valuable contribution to the development of the Tailor Made model of care and resource kit. We also sincerely thank the many voices of younger people with dementia and their families* who told us their stories. Sincere thanks also to the service providers who shared their knowledge and experiences of supporting people with younger onset dementia.

This project is funded by the Commonwealth Department of Health through an Aged Care Service Innovation and Healthy Ageing Grant.

*Anyone in close association with the person with dementia can be regarded as a ‘family member’ regardless of whether or not they are related.

Acknowledgements

Lesbian, Gay, Bi-sexual, Transgender and Intersex (LGBTI Specific Services
Gay and Lesbian Community Services
South Australia
A not for profit, community based organisation providing support, information and resources to the gay and lesbian community in South Australia.
Website: glcssa.com

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Whilst every effort has been made to ensure the accuracy of this resource kit, the author cannot accept or assume any responsibility or legal liability for its use, including liability for negligence, for errors or oversights in the information provided. This material is general in nature and gives an overview of respite options and issues for younger people with dementia and their families and will not provide ALL the information needed on this topic. Independent professional advice should be sought about specific issues. The project team was Lenore de la Perrelle, Manager of the Dementia Learning and Development Unit, ACH Group, Senior Project Officer, Kelly Quinlan and Project Officer Teresa Moran. Produced and Printed in South Australia.
Founded in 1952, ACH Group is a not-for-profit community organisation promoting opportunities and services to support good lives for older people.