

Caladenia Dementia Care

Information for Members and Carers



CALADENIA DEMENTIA CARE.

Providing superior services to enhance the quality of life for people living with dementia

INFORMATION FOR CARERS

OPERATION OF THE DAY PROGRAM

Caladenia employs trained staff and volunteers, assisting with the Programs and during bus transport times.

- Venue:** Meadowbank House,
11 Hilledge Lane,
Mooroolbark Vic 3138 (Melway 37H6)
- Telephone:** 9727.2222
- Fax:** 9727.3787
- Email:** caladenia@caladenia.com.au
- Web Address:** www.caladenia.com.au
- Day Centre Hours:** Monday - Friday
8.30am to 4.30pm.
- Program Hours:** Monday & Tuesday – 10am – 3:30
Friday - 10am - 2.30pm.
Thursday – 10am – 6:30pm
Sunday - 11am - 5pm (2 Sundays a month)
Men's Program- Fridays
- Fees:** Program day fee - \$8.00
Fees are negotiable, and consistent with the HACC Fees Policy. Fees may be waived in certain circumstances, and no client will ever be refused service because of an inability to pay. Please contact the co-ordinator for further information
- Lunch:** A balanced home-style, light meal is prepared and provided at the Centre. Special diets can be catered for.
- Transport:** The Centre twelve-seater bus is available for transport to and from Caladenia as seating allows. A paid driver and a volunteer accompany members on each bus run to ensure a safe and considerate trip, and to provide reassurance and gentle guidance as required.

THE PROGRAM:

The daily Program is based on the model of “Person Centred Care” and is flexible and responsive to the needs of members. Activities of varying diversity are offered, with recognition of members’ interests, limitations and changing moods, to ensure an enjoyable and meaningful day in a safe and secure environment.

Members are given encouragement, but are never forced to participate in an activity. Ongoing assessment allows staff to identify needs, and enables planning for the Program. Evaluation, which is also ongoing, allows the Program to remain responsive to member’s needs and wellbeing. The Program constantly undergoes changes to accommodate members' interests and ability to participate.

The carer is the most important person in providing information which will assist staff and volunteers to become familiar with each member’s interests & needs.

AIMS OF CALADENIA DEMENTIA CARE PROGRAM:

- * To create an environment of friendliness, safety, predicability and acceptance that will relieve fears and anxiety.
- * To promote a sense of belonging, and establish some order in the member’s disorientated world.
- * To provide quality of life via a program of varied activities, stimulation and socialisation.
- * To maximise a member’s abilities by identifying and providing appropriate activities aimed at increasing self-esteem.
- * **To focus activities to:**
 - Ensure group interaction and socialisation
 - Reinforce sense and identity, increase self awareness and orientation.
 - Highlight sensory experiences.
 - Maintain independent living.
 - Decrease anxiety, restlessness and wandering.

Providing :

- Musical activities.
- Movement, dance and gentle exercise.
- Reminiscence.
- Quizzes & word games.
- Local walks and bus outings.
- Liaison with community groups /schools.

CRITERIA FOR ATTENDANCE

A diagnosis of Dementia.

This diagnosis needs to be made by a medical person ie General Practitioner (GP), neurologist, psycho-geriatrician, psychiatrist or ACAT Team

Referrals can be from many sources. For Example: GP's, District Nurse, Family Members, Aged Care Assessment Teams, Carer Respite Centre, Shire Assessment Team, families or self referral.

On receiving a referral at Caladenia, the staff will ensure the Carer/s is contacted. An appointment will be made with the carer/s and the potential member to do an agency assessment. This appointment may take place at Caladenia or in the prospective member's home.

An appropriate day will be decided for the member to commence, preferably with the carer transporting and present in the Program on the 1st visit for a short time and subsequent visits should there be a need.

The allocation of days of attendance will be decided by the assessment, the needs of the group, individual needs and staff ratios. If there is a waiting list in operation at the time of the assessment, the carer/s will be advised as to the wait list procedure and the expected time of the wait.

As a HACC client you have the right to refuse a service provided by Caladenia Dementia Care. Should you choose not to commence, appropriate information will be provided to you, or you may speak to the Manager regarding referral to another service. Please note that clients who refuse service, or choose not to commence are able to be re-referred at any time.

As a HACC Client you have the right to appeal a service provision decision. Clients and their carers have the right to appeal the decision of the day centre regarding discharge. Discussion will be held with the Manager and the client /carer

Members will be discharged if behaviour is disruptive to the group and, after trying different strategies, this behaviour cannot be managed. Members who exhibit violent behaviour will be discharged. Members may also be discharged if they enter permanent residential care, if there are incontinence issues that cannot be managed by the program staff, if a member's physical support needs are no longer able to be managed at the centre, or if the client/and or carer is no longer receiving any benefit from the service. This will be discussed with carers and support, referral and advice will be provided.

As the members dementia progresses it may be necessary to move them to a group consistent with their stage of dementia. This is to ensure activities offered are going to meet their needs. This will be discussed with the Carer.

STAFF AIMS FOR CARERS.

- * Confidentiality at all times.
- * Access to information about the programs and dementia.
- * Individual consultation and support with Caladenia staff.
- * Monthly Carer Meetings for support, information sharing and “Care and Share” opportunities.

STAFF REQUESTS OF CARERS.

- * Carers agree to, and respect, the commencement (9.45 - 10am) and departure time (3.30 - 3.45pm), as it is unsettling for the members if the time schedule is interrupted.
- * Staff to be kept informed of relevant information pertaining to the care of a member. Staff need to be informed of any allergic reactions to medication and/or food.
- * Carers or voluntary drivers transporting members to the Centre take the responsibility to escort members into the Centre, and ensure that a staff member is aware of their arrival and departure.
- * Carer/approved representative to be at home to receive the member on his/her return from the Day Centre. For those members that live alone or Carers are not routinely available, arrangements need to be made to ensure the member is safe to be left alone.
- * If a member who uses the Centre bus is unable to attend the Program, where possible, please contact the Coordinator the previous day, or between 8.30am. and 8.45am on the Program day, on phone 9727 2222, to cancel transport arrangements.
- * The Manager or Program Leader to be notified if a member has a problem with continence. The carer is asked to send a change of clothing and the appropriate continence aids to the Centre.
- * The member is appropriately clothed during warm/cold weather.

CARERS’ SUPPORT GROUP MEETINGS.

It is recommended that carers attend the Caladenia Carers’ Support Group Meetings, held at Caladenia Dementia Care. This meeting provides carers with an opportunity to discuss their needs, to receive support and advice and to assist them to care for a loved one with dementia. Everyone is welcome.

Please do not hesitate to contact the staff with any queries or for further information required.

SERVICE OPTIONS

There are many service options available to people living in the Shire of Yarra Ranges. These include Council Services, Delivered Meals, Case management, Carer Respite and other Planned Activity Groups. If you would like more information – please discuss this with the staff who will; be happy to provide you with information, referral (with your permission) and support.

In their Words

Approaching situations from the person living with dementia's viewpoint enhances the quality of care. Reproduced with permission from Jane Verity – CEO Dementia Care Australia

As a care provider going into the room or home of a person with dementia, you may have encountered unpleasant and unexpected challenges where you asked yourself, what could I have done differently to avoid this situation?

Written in the voice of the person with dementia, this article enables you to discover their experiences.

You will learn the secrets to prevent stressful situations by seeing each interaction from their point of view and understanding their special needs.

The suggestions discussed have all been trialled and tested in real life with great success. You may find it beneficial to read these ideas several times as there are various subtle hints to discover. The secret to success lies in focusing on the small details in your everyday interactions with the person who has dementia.

When you go into the home or room of people with dementia, you are their visitor. Take every opportunity to empower them with the feeling that they are in charge and have your full respect.

The thoughts and feelings of the person with dementia begins:

If you want to come into my home, I need to feel comfortable and think of you as my special friend. I do not need help – I am doing fine. I have looked after myself all my life, taken care of my family; I do not need you to come in here and take over running my life.

Who are you?

When you come to my door, I may not recognise who you are, remember your name, nor why you are here. This is no reflection on you but on my memory so I need your help. Put me at ease so I can trust you and feel comfortable to open the door and welcome you in. Say hello and use my name so I can realise that we know each other. Then say your name and the relationship we have. I prefer to think of you as a special friend, so this could sound like, “Hi John, I’m Simone, your special friend from Council Care”.

What are you doing here?

You need to know I am “allergic” to receiving help or support so rather than telling me you are here to help, which may result in me telling you to go home, tell me you have come to say hello and see how I am. Once I have let you in, and we have said our special greeting, you could say “While I am here, what if I give you a hand with the cleaning?” When you suggest giving me a hand, you are implying that I am still in charge and I like that. If you come in, pull out the vacuum and tell me you are cleaning up, I am likely to take offence as I feel you are taking over. Remember, my home or room is my castle.

My Clothes

The same applies to my personal clothes when you give me a hand in the shower – they are an extension of me. Never throw them on the floor nor tell me they are dirty. I will immediately think you are telling me that I am dirty, which is bound to make me angry and argumentative. Instead, carefully hang my clothes on a coat hanger. Then, while I have a shower gently move the clothes that need washing out of my sight, replacing them with fresh clothes.

Going to the toilet

If I use continence pads, or I have had an accident, never tell me that they are soiled or dirty, or that I need “clean” underwear. I hear these words as an insult and may become indignant and difficult. Instead, I prefer the words fresh, and freshen up. You could say, “What if I give you a hand freshening up once you have been to the toilet?” This reminds me, I do not like constant prodding that I need to go to the toilet. If you ask me, “Would you like to go to the toilet?” I am likely to respond with a strong, no! If I am a woman you could try saying, “I need to go to the toilet, are you coming?” If I am a man you could say, “After everything we have had had to drink, nature calls. Come on!” Keep it simple and a matter of fact.

See you next time

When it is time for you to leave, I like it when you tell me how much you have enjoyed spending time together and that you look forward to seeing me again. I may even respond in the same manner, which means I have had a positive experience. This is how you can become my special friend.

Jane Verity is CEO of Dementia Care Australia.

www.dementiacareaustralia.com or (03) 9727 2744

‘THE OTHER DEMENTIAS’

Dementia is a term used for loss of mental function to the extent that this interferes with the person’s daily life. It is not a disease in itself but rather a group of symptoms which accompany certain diseases. It is a very broad term which describes a loss of memory, intellect, rationality, social skills and normal emotional reactions. Alzheimer’s disease is the major cause of dementia. Dementing illnesses can affect adults of any age, although they are more likely to occur in late years.

WHAT ARE THE MOST COMMON FORMS OF DEMENTIA?

ALZHEIMER’S DISEASE is the most common of the dementias and accounts for about 68% of all cases.

VASCULAR OR MULTI-INFARCT DEMENTIA is the result of many small strokes and is the second most common form of dementia. These strokes may damage any area of the brain responsible for a specific function. If many, they produce generalised symptoms of dementia. As a result, vascular dementia may appear similar to Alzheimer’s. It is not reversible or curable, but recognition of any underlying condition (high blood pressure) often leads to a specific treatment, which may modify its progression.

This form of dementia is usually identified through a neurological examination, which identifies strokes in the brain, and is confirmed on a brain scan.

Note: The co-existence of Alzheimer's Disease and vascular dementia is also common (about 25%), These people usually have a progressive dementia and disorders associated with a stroke such as smoking, diabetes, hypotension and heart disorder.

PARKINSON'S DISEASE (PD) is a progressive disorder of the central nervous system, characterised by tremors, stiffness in limbs and joints, speech impediment and difficulty in initiating physical movements. Late in the course of the disease, some people develop dementia. Medication can improve diminished motor symptoms.

ALCOHOL. Too much alcohol, particularly if associated with poor diet and blackouts and frequent falls, leads to irreversible brain damage. The most vulnerable parts of the brain are those used for memory, higher cognition tasks such as planning, organising and judgement, social skills and balance. If drinking ceases, there can be some improvement. Thiamine, a vitamin, is important to limit some of the toxic effects of alcohol, and is an important supplement for heavy drinkers.

INFECTION. Some forms of dementia are due to infection. The most common of these in the past was syphilis and today AIDS-related dementia is common late in that disease.

HUNTINGTON'S DISEASE is an inherited, degenerative brain disease, which affects the mind and body. It usually begins during mid-life, and is characterised by intellectual decline and irregular, involuntary movement of the limbs or facial muscles. Other symptoms include personality change, memory disturbance, slurred speech, impaired judgement and psychiatric problems. Diagnosis includes an evaluation of family medical history and CAT brain scanning. There is not treatment available to stop the progression of the disease, but medication can control movement disorders and psychiatric symptoms.

PICK'S DISEASE is a rare disorder of the frontal part of the brain which is usually difficult to diagnose and affects people usually between the ages of 40 and 65. In a small number of cases, Pick's Disease will affect the temporal rather than the frontal lobes of the brain in the early stages. Disturbances of personality, behaviour (particularly lack of inhibitions) and orientation may precede and initially be more severe than memory defects.

The causes of the various forms of Pick's Disease are not yet known but it is thought that one form of the disorder, which accounts for a small number of cases, runs in families.

CREUTZFELDT-JAKOB DISEASE is a rare fatal brain disorder caused by a transmissible infectious organism, probably a virus. Early symptoms include failing memory, changes of behaviour and a lack of coordination. As the disease progresses, usually very rapidly, mental deterioration becomes pronounced, involuntary movements appear, and the patient may become blind, develop weakness in the arms or legs and ultimately lapse into a coma.

HEAD INJURY. Head injury, if severe, can produce permanent change in a person's ability to think and in their behaviour and personality. Usually this follows only if a person has been unconscious for a long time.

DEMENTIA-LIKE SYMPTOMS WHICH ARE TREATABLE. Serious forgetfulness and some other dementia-like symptoms sometimes are caused by a condition, which can be cured. When such a condition is treated appropriately, the memory improves. Therefore, it is important for anyone with dementia-like behaviour to seek a thorough assessment to find the cause.

If you would like more information on dementia, or would like to access the services of the Alzheimer's Australia Victoria:

- * Counselling
- * Support Groups
- * Library
- * Education
- * Telephone Information & Referral
- * Newsletters

Please contact : **98 Riversdale Road,
Hawthorn 3122**
Freecall: 1800 100 500
Telephone: 9818 3022
Facsimile: 9818 3940

Privacy Statement

Caladenia Dementia Care is committed to respecting the privacy of your personal information.

Caladenia is bound by a set of National Privacy Principles that are the benchmark for how personal information should be handled. Caladenia has adopted these principles as part of our standard business procedures.

What this means is that all personal information that enters Caladenia is dealt with in a uniform manner and the highest regard is taken for maintaining its security at all times.

Caladenia holds contact information about its consumers, including date of birth, next of kin information, and some medical details. It also holds limited financial information.

The main purpose for which Caladenia holds this information is to assess the need for Caladenia's services, to make decisions about the level of care a consumer will require, and to ensure the safety of all consumers at all times.

Caladenia may, from time to time, disclose some of this personal information to the Commonwealth and State Governments or their agencies. This will be in accordance with the provisions of all relevant legislation and regulations that apply to Caladenia and all its services, and for the purpose in informing decisions about funding and meeting medical, social and other care needs. The Commonwealth and State Governments are also subject to laws dealing with privacy, and have their own policies that are designed to safeguard your personal information.

If you are concerned that Caladenia may have handled your personal information inappropriately, please contact the Manager on 9727 2222. All privacy complaints will be taken seriously and we will endeavour to deal with them promptly. In some cases we may require that you put your complaint in writing.

If you would like to request access to any personal information held by Caladenia, please contact the Manager. The Manager will arrange for an access form to be sent to you, and is able to assist with any enquiries you may have regarding the process.

Caladenia will respond to all requests within 28 days, and in most cases will be able to respond well before that time.

Statement of Rights and Responsibilities

1. Preamble

People with dementia and their carers make up Caladenia's Target Group. In this statement, any reference to the consumer is intended to apply equally to all members of the target group.

The HACC Statement of Rights and Responsibilities recognises that:

- The Program assists people who are at risk of premature or inappropriate long term residential care and their carers.
- The Program aims to enhance the quality of life and independence of those "at risk" people and their carers.
- The Program is administered and in accordance with the principles and goals set out in the HACC Agreements
- Consumers of HACC services retain their status as members of Australian society and enjoy the rights and responsibilities consistent with this status.
- Providers of HACC services operate under the constraints of relevant law.

2. Consumer Rights

The key rights, which affect consumers of HACC services in their relationship with Caladenia Dementia Care, are:

- The right to respect for their individual human worth, dignity and the right to privacy.
- The right to be assessed for access to services without discrimination.
- The right to be informed about available services.
- The right to choose from available alternatives.
- The right to pursue any complaint about service provision without retribution.
- The right to involve an advocate of their choice.

3. Service Provider Responsibilities

In providing services, Caladenia Dementia Care has the responsibility:

- To enhance and respect the independence and dignity of the consumer.
- To ensure that the consumer's access to service is decided only on the basis of need and the capacity of the service to meet that need.
- To inform the consumer about any options for HACC support open to him or her.
- To inform the consumer of his or her rights and responsibilities in relation to HACC services.
- To involve the frail elderly person, the person with dementia and/or their carer in decisions about the assessment and service delivery plan
- To negotiate with the consumer before a change is made to the service being provided.
- To be responsive to the diverse social, cultural and physical experiences and needs of consumers.
- To recognise the role of the carer, and to be responsive to his or her need for information, referral and support.
- To inform the consumer of the standards to expect in relation to the services he or she may receive.
- To ensure that the consumer continues to receive services agreed upon with Caladenia, taking the consumer's changing needs into account.
- To respect the privacy and confidentiality of the consumer.
- To allow the consumer access to information about him or her held by Caladenia.
- To allow a carer access to information held by Caladenia about the consumer where the carer is the legal guardian or has been so authorised to do so by the person receiving care.
- To deliver services to the consumer in a safe manner.
- To respect the consumer's refusal of a service and to ensure that any future attempt by the consumer to access a HACC service is not prejudiced because of that refusal.
- To deal with a consumer's complaints fairly and promptly and without retribution.

- To mediate and attempt to negotiate a solution if conflict about a service arises between the carer and the service recipient.
- To accept the consumer's choice and involvement of an advocate to represent his or her interests.
- To take into account the consumer's views when planning, managing and evaluating HACC service provision.

4. Consumer Responsibilities

Consistent with their status as members of Australian society, HACC consumers have a responsibility:

- To respect the human worth and dignity of Caladenia Staff, Volunteers and other consumers.
- For the results of any decisions they make.
- To play their part in helping the service provider to provide them with service.

For more information, contact the
Department of Human Services
Phone – 9843 6000

Advocacy

What is an advocate?

There are several different definitions of the word advocate or advocacy. Many have a legal context, *The Macquarie Dictionary - 2nd Revised Edition (1988)* offers the following definitions:

- Advocacy** - “an act of pleading for, supporting or recommending; active espousal”
- An Advocate** - “one who defends, vindicates, or espouses a cause by argument; an upholder; a defender”
- (to) Advocate** - “to plead in favour of: support or urge by argument”

A more relevant description of an advocate, in the context of HACC providers however, can be found in a definition of advocacy from *Advocacy Tasmania Inc*, who describe advocacy as **‘the process of standing beside an individual or group and speaking out on their behalf to protect and promote their rights and interests’**.

The role of an advocate

The role of an advocate is to **‘stand beside or behind’** a consumer and to support them in decision making and ensuring that their rights are respected. An advocate **does not** take over or make decisions on a person’s behalf. An advocate can be involved and be with a consumer at any time, including through the assessment or reassessment process or if the consumer wishes to make a complaint about the service. It could be a one off or an ongoing relationship.

Who can be an advocate?

An advocate can be anyone the consumer nominates. It could be:

- A primary carer
- A family member
- A friend or neighbour
- Another service provider
- Staff – except if there is a conflict of interest

Caladenia Dementia Care will ensure that all clients and their carers have access to an advocate of their choice to represent their interests at anytime.

Procedure:

- ◆ Caladenia will develop links with local advocacy groups and services.
- ◆ Caladenia will inform all clients and carers of the availability of advocacy assistance at the time of the initial assessment.
- ◆ The Manager will, upon request, refer clients to the advocate of their choice.
- ◆ The Manager will provide information to the advocate – but only with the written permission of the client.

- ◆ Staff will notify the Manager if any client requests an advocate.
- ◆ Staff will identify situations where an advocate may be required and inform the Manager.

Caladenia Dementia Care Inc

Advocacy Organisations

1. Mooroolbark Community Centre
P.O. Box 350
Lilydale, 3140

Phone: 9735 1311
2. St John of God Services
12/96 Manchester Road,
Mooroolbark, 3138

Phone: 9727 2466
3. St John Of God Services
Nunawading

Phone: 9738 1452
4. Outer Eastern Citizen's Advocacy Bureau
17 Greenwood Avenue
Ringwood, 3135

Phone: 9879 5206