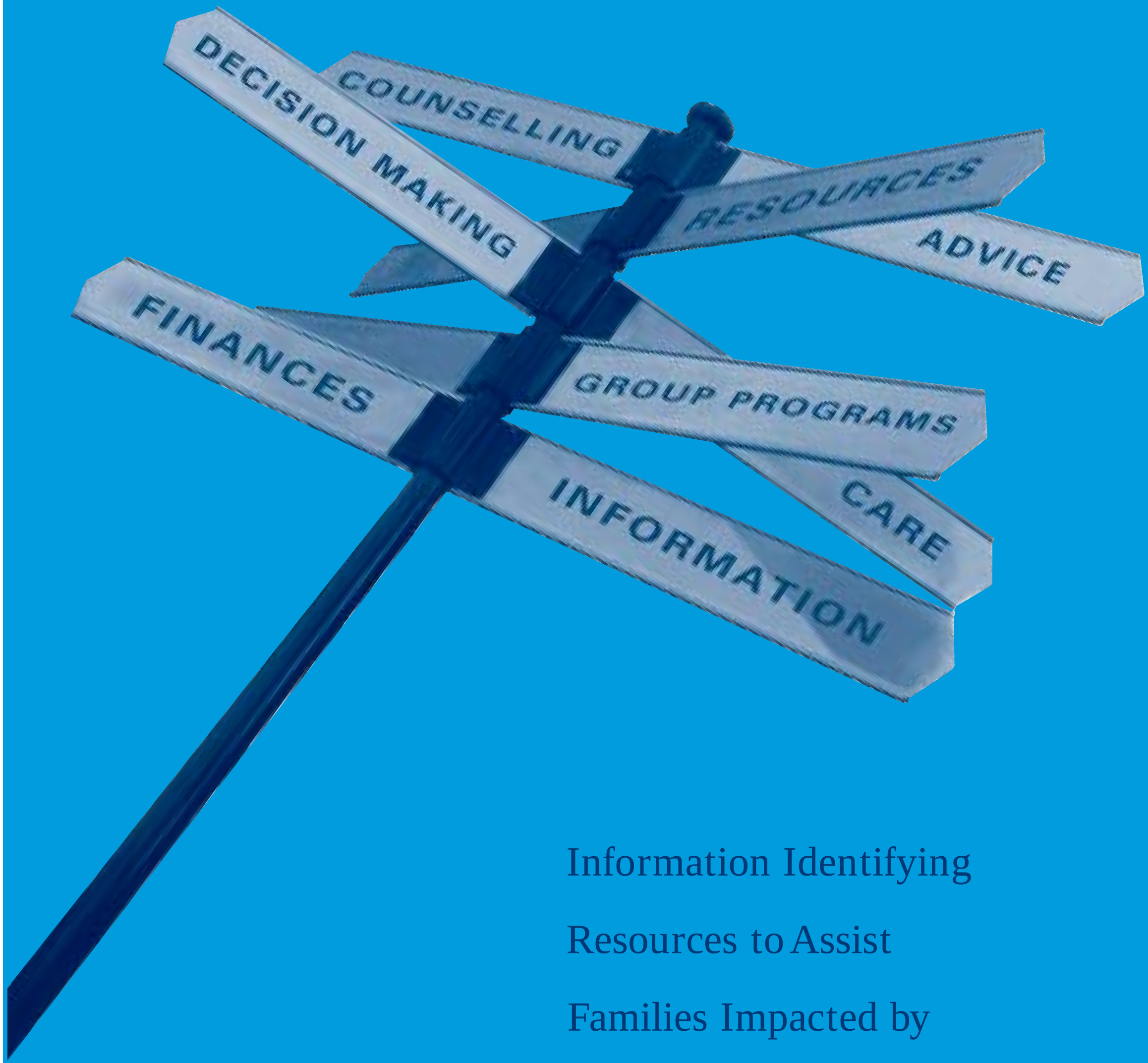
SIGNPOSTS



Information Identifying Resources to Assist Families Impacted by Dementia Beginning Prior to 65 Years of Age

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Rosemarie Tweedie and Lisa Lovi
Alzheimer's Australia NSW
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Written by Rosemarie Tweedie and Lisa Lovi
Alzheimer’s Australia NSW

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Alzheimer’s Australia NSW Incorporated
Vincent Fairfax Family Resource Centre
Macquarie Hospital Campus
Cox’s Road Entrance
North Ryde NSW

Postal Address
PO Box 6042
North Ryde NSW 1670

Administration Telephone
02 9805 0100

Facsimile
02 9805 1665

Email
admin@alznsw.asn.au

Library email
library@alznsw.asn.au

Website
www.alzheimers.org.au

A copy can be obtained by downloading from the website, telephoning or writing to the Helpline at the above address or telephoning1800 639 331.

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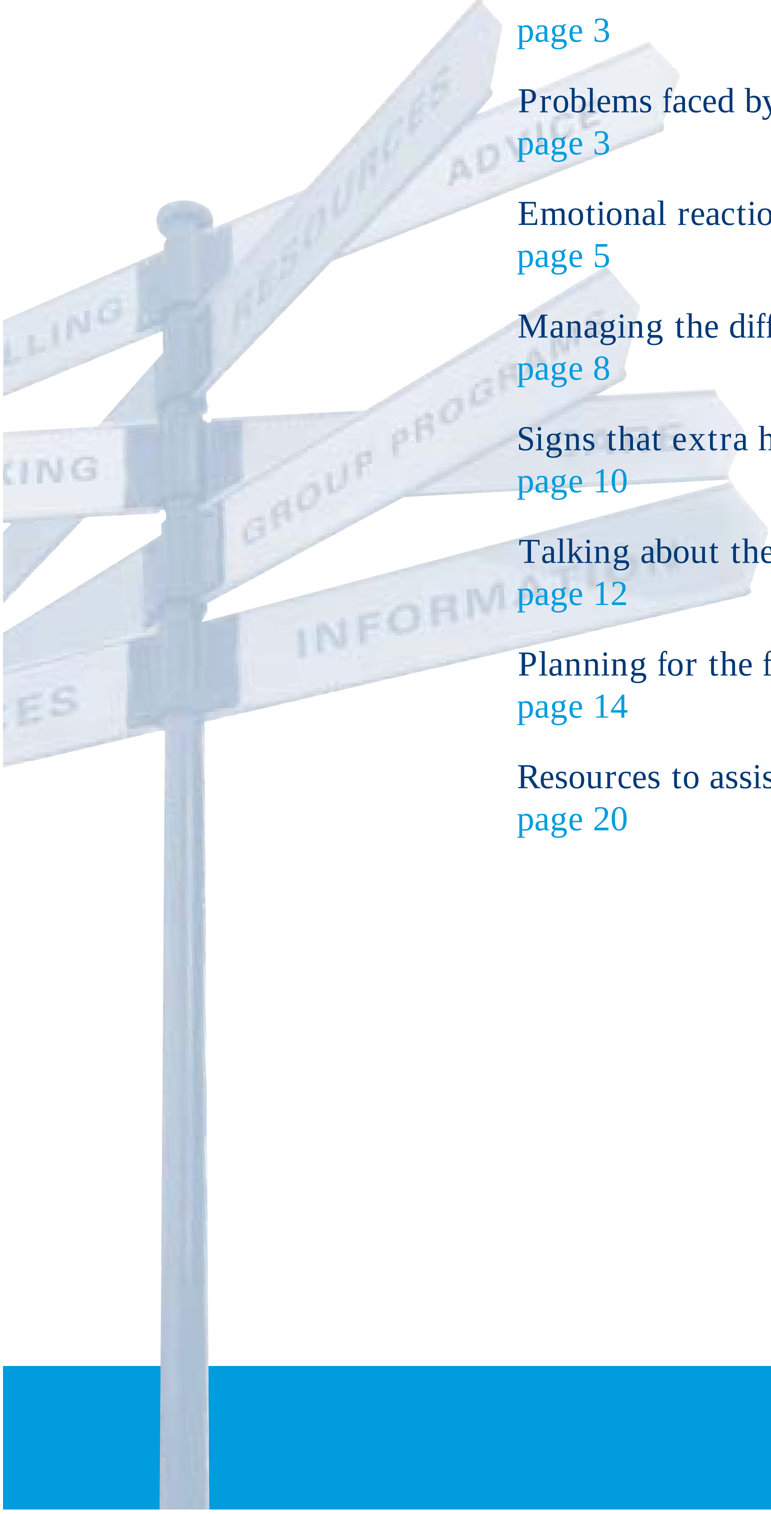
This publication provides a general summary only of the subject matter covered. Any person with dementia or a carer for person with dementia should seek professional advice about the specific case. Alzheimer’s Australia NSW is not liable for any error or omission in this publication, even if negligent.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ABOUT ‘SIGNPOSTS’

Purpose

- To provide resources to assist families where a diagnosis of younger onset has been made.
- To assist family members to more easily find the information and resources they need to manage this demanding time.
- To assist health professionals in working with this unique group of people.

How to use *Signposts*

- *Signposts* is intended to provide basic, useful information, rather than being an exhaustive source of knowledge for family carers of people with younger age onset dementia.
- It includes telephone numbers and sources of further information that can be accessed when needed.

What is Younger Onset Dementia?

- Often the terms early onset or younger onset are used interchangeably to refer to dementia that occurs in those who are have been diagnosed with dementia under the age of 65 years. The majority of those who have this diagnosis are between 50 and 65 years old but there are also many younger than 50. However the term that describes this dementia is younger onset dementia. It should not be confused with early stage dementia as this term refers essentially to those who are in the early stages of the disease at any age.
- Information as to the rates of this dementia varies. One rate suggested is that about 1 in 1000 people will develop dementia before the age of 65.[1]
- The person diagnosed and their families will experience many problems that are similar to those who are older when diagnosed; but there will also be many that are specifically related to this age and stage of life.

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[1] www.alz.co.uk (Alzheimer’s Disease International)

SPECIFIC CHARACTERISTICS OF THOSE DIAGNOSED WITH YOUNGER ONSET DEMENTIA

As this diagnosis often comes in ‘the prime of life’ it is usually unexpected, and often the person:

- Is still working and has significant financial commitments.
- Has a younger family.
- Has more responsibilities not only within their immediate family but in their extended family and the community.
- Will be more aware of the disease in the early stages.
- Will have to manage a wide range of responses to their diagnosis because of the above, and manage more confusion and uncertainty regarding their health.
- May experience a lack of knowledge or understanding of younger onset dementia by the medical profession.

PROBLEMS FACED BY THOSE WHO ARE YOUNGER WHEN DIAGNOSED

Impact on the person diagnosed with dementia

The person will experience a range of the following feelings:

- Significant shock, anger, being overwhelmed, as the diagnosis is usually totally unexpected due to their age.
- Fear of the unknown.
- May suffer financial difficulties as a result of the disease.
- The difficulty of having to end work or career prematurely, and learn to adapt to a very different style of life.
- Can feel hurt or rather confused by the reaction of others to their illness. This can vary from disbelief/horror/fear/confusion from friends, and many friends may distance themselves as the illness proceeds. This can happen when the person diagnosed is older, but often is more extensive when he/she is younger.
- Can feel their experiences are being trivialised by the statements that some people in their network may make. For example, ‘I have trouble remembering things too.’

- In the early stages, many of those diagnosed will have insight into what is happening to them, and many will have assumed that this was a disease of an older person, not someone their age.
- The person diagnosed may want to participate in decisions regarding the future and yet can be, or feel left out of the consultation process because of their diagnosis.
- The person will need to slowly address and grieve their ongoing disconnection to their social and emotional world.

Impact on partner

- The partner will experience many of the above feelings and reactions as well.
- The partner of the person diagnosed will have his/her life upturned as well and find it very difficult to accept the diagnosis. There is the significant loss of physical and mental abilities, loss of companionship, intimacy and the future of the relationship. In addition to these changes there may be dependent children whose needs still continue.
- After diagnosis, rapid changes will take place within the partnership. During the early stages the partner will often have to initiate, support and plan for the two of them as they address the impact of the diagnosis.
- Issues regarding work, family finances, disease progress, children’s needs and relationship changes will need to be addressed in some way.
- The person diagnosed needs to be included in this process as much as possible.
- There will be changes in the sexual relationship between the couple and for many this may become a problem area. Some carers will find it hard to maintain a sexual relationship due to other changes in their life, while for some it will continue to have meaning. As the illness progresses there will be further changes and challenges. For example there may be increased sexual demands, lessening sexual interest and/or loss of inhibition.

See the Resources section for more information.

Impact on family and friends

- Relatives and friends initially will also experience a range of feelings similar to those listed previously on hearing of the diagnosis. This will include feeling shocked and surprised and possibly helpless. This may limit the amount of support and assistance they can initially provide due to their own reactions about the diagnosis, their shock and feelings of helplessness and grief. Often the person with dementia or the carer will need to take the initiative in reaching out to specific relatives or friends, so as to garner their emotional or

practical support. Often when family members or friends understand how they can be of assistance and that they are needed in some way, they are more able to overcome their feelings of helplessness or their desires to avoid.

- Depending on the age of the children, they will also have similar reactions. A younger child (prior to adolescence) is more likely to experience bewilderment and general confusion, and be less able to articulate specifically their range of feelings. Often very young children will feel as if they might ‘have caused’ the disease in some way and feel responsible for what is happening to their parent.
- A diagnosis of dementia will often disrupt stages of family transition and development. For example, a child needing to stay at home to assist in managing the care of their parent, may be hampered or find it impossible to participate in sport on the weekend.
- Young adults may feel ‘trapped’ at home and experience difficulties in progressing towards achieving independence in their lives, in areas such as continuing with studies and training, or the ‘rite of passage‘ of leaving home.

Underpinning principles associated with this diagnosis

- This disease is a health issue and is not confined to the elderly.
- A person with dementia has the right to be treated with dignity and have access to appropriate services.
- The challenge for the person with dementia and the family is to learn to live with dementia and to negotiate the transition times throughout the pathway of the dementia.
- The person with dementia always has understanding (at varying levels) and therefore needs to be included in day to day decision making as well as future planning.

EMOTIONAL REACTIONS IMMEDIATELY AFTER DIAGNOSIS

The period after receiving a diagnosis or possible diagnosis is an extremely difficult time as the person diagnosed and those close to them experience their world ‘falling apart’. It is traumatic and overwhelming and often time is needed to reflect about the diagnosis and its potential impact. Some may manage this difficult time in a variety of ways by:

- Being practical in seeking information and beginning to plan.
- Withdrawing or becoming almost immobilised for a time.
- Needing to talk with close family and/or friends to start to understand the possible implications.
- Throwing themselves into physical activities.

It is important to know that there is no ‘right or wrong’ way for this process.

The person with the diagnosis, the partner, friends and relatives, may all experience these reactions but the strength of these will inevitably vary.

Helplessness

Being told the person's condition will deteriorate, and that there is very little that can be done to halt this process can trigger overwhelming feelings of helplessness. Some of the questions asked will be:

- How will we cope?
- How will I manage the disease when it becomes worse?
- How will I survive?

Anger and 'Why Me'

Often part of the process can be strong feelings of anger and asking the questions associated with 'why is this happening to us?' There is significant loss associated with this disease, which can trigger anger as well as grief. What about our plans for travel? What about our plans for life after the children leave home? Will we be able to stay in our house?

Significant shock

Hearing the news that you or your partner has a diagnosis of dementia will often send a person into shock – not really knowing what questions to ask or what to do is a part of this reaction. Feeling numb can also be part of this process. Again, this is not an unusual reaction, and the strength of this will reduce over time; but part of the feelings may remain quite a long time. Another response soon after the diagnosis may be to feel quite 'panic stricken' or paralysed and unable to act.

Relief

There can be some feelings of relief on hearing the news especially if there has been ongoing concern and confusion about unexplained unusual or 'out of character' behaviours by the person diagnosed. The relief can come from at least knowing that there is a physical cause for this behaviour, but this will also be mixed with other reactions.

Guilt and shame

When there is a realisation that certain problematic aspects of a person’s behaviour have been due to a physical condition, there may be guilt or shame about recent arguments or comments that have been made ‘in the heat of the moment’. These feelings can be quite unpleasant.

Distress

Receiving such a diagnosis is very distressing and each person will express this distress in varying ways, including crying a lot, talking with a friend or seeking help and information. Some carers (often male) may respond in other ways, which may include withdrawal from social contact or focusing their energy on physical work or activity to assist in gaining a sense of control, or distancing themselves from the complexity of the problems.

Grief

Often the diagnosis will trigger a process of grieving which will continue throughout the disease process in varying degrees of intensity. The difficulty of this grief is that at times it will be all consuming and often there may be a sense that others do not understand their emotional state (and often that will be part of the reality).

It is important to remember that grief is a normal response to loss and continues in many forms through out the journey of the disease. The losses that people with dementia and their family carers experience are significant and many and include the following:

- Previous levels of cognitive abilities.
- Previous levels of physical abilities and functions.
- Dreams and expectations of the future of the relationship and of their life together.
- A sense of security.
- A hope for future.
- A sense of a degree of predictability and control over life.

If you are feeling overwhelmed by these reactions…

The previous relationship that the carer (and others) had with the person with dementia will change in many ways, and new ways of relating and communicating will be required. This is a learning process, which will take time, information, support, patience and forgiveness. It will be important to look at ways of building up personal, social and physical resources to place oneself in the best possible position to be able to manage and cope with the changes that lie ahead. The next section provides some ideas on how this might be able to be achieved.

MANAGING THE DIFFICULT PERIOD IMMEDIATELY AFTER DIAGNOSIS

How is help accessed?

- Via the Dementia Helpline or a Regional Advisor or General Practitioner or Aged Care Assessment Team (ACAT).
- It is helpful to speak with a person who knows and understands about dementia and how the diagnosis may be impacting. These services can provide current information, and are familiar with the range of tumultuous feelings and concerns of the person with the diagnosis and family members. These services can provide information about the next possible and useful steps.
- Some family members or the person with the diagnosis will find a General Practitioner can be a source of information about the disease as well as information for accessing appropriate services.
- Those impacted by the diagnosis need to find some ‘safe’ friends with whom to talk and share what is happening. All those impacted need to be able to talk over the implications of the diagnosis with others of their choice.
- Another source of information is the internet.

See the Resources section for more information.

What is available in the community to assist the family soon after diagnosis?

- Counselling can provide people with an opportunity to discuss in detail the impact of the diagnosis and the resulting changes they are experiencing. Counselling can help people to identify further sources of assistance and to develop a plan to better manage this difficult time.
- Specialist medical services in physical and mental health.
- Group programs such as:

  In NSW, a structured seven-week education and support program is conducted for people in the early stage of Alzheimer’s disease or another dementia, and their families and friends. This is called the *Living with Memory Loss Program*.

Throughout NSW there are over 170 Support Groups that usually meet monthly to provide information, mutual problem solving and sharing of ideas. Many carers find that the group provides a 'safe haven' to discuss issues that are difficult to talk about with people in one's usual social network.

Occasionally there are telephone support groups established throughout the state.

- ⓘ Information (journals, books, Helpsheets, videos) via internet and libraries, particularly Alzheimer's Australia NSW Library & Information Service.
- ⓘ Education – Many areas in NSW run structured dementia educational sessions led by health professionals.
- ⓘ Community support services, for example, respite care, day centres and homecare services.

See the Resources section for more information.

Further along the journey – how can a social network be maintained and developed?

One of the ways to manage throughout this time is to foster and maintain a strong social support network. Maintaining a variety of relationships can work to provide support, ideas, mutual problem solving and normality, both for the person diagnosed and the carer. Both experiences can be lonely and isolating, and so spending time reflecting on and planning an effective social support network can be worthwhile, despite the effort that is required at this difficult time.

Why is a strong support network important?

- ⓘ Closer social ties with others assist to be less vulnerable to depression.
- ⓘ A wider social support network offers many more physical and emotional resources to a person as well as offering differing points of view for problem solving.
- ⓘ Adequate social support works to keep a person feeling more positive about themselves.
- ⓘ Isolation from relationships reduces a person's capacity to cope and effectively problem solve.

Obviously there will be periods of time when there will be no time for talking to others or 'reaching out' to maintain relationships. However at other times this will be possible.

Ways of maintaining and expanding the social support network at this difficult time

- Think of ways to develop a current relationship by talking more openly about daily experiences, or plan to spend more time together. Some ways to do this include organising an activity together, talking more often on the phone, or if practical, invite the person over.
- Are there any relationships or friendships from the past that can be rekindled? Is there a person with whom there was regular contact who could be re-contacted?
- Can new friendships be started or formed? This can happen through an existing organisation, through a support group network or someone who lives close by who can be visited, in person or via the phone.

A social support network/team can assist you in your journey of dementia.

Even if some family members or friends are unable to offer the understanding that may be sought, they may still be able to offer a sense of normality, and to help the carer or the person living with dementia maintain a part of themselves outside of the caring role or the diagnosis. Staying separated from extended family and relationships may be a normal reaction for a period of time after the diagnosis. However if this pattern continues over a long period of time, it will be detrimental for both the carer and the person with the diagnosis.

SIGNS THAT EXTRA HELP MAY BE NEEDED

Many carers of people diagnosed with dementia experience anxiety and depression. Early assistance can help in preventing a deterioration of symptoms, which might result in even greater difficulties in being able to cope with the situation.

It is important for the carer to seek assistance from either their nearest doctor or mental health service if the carer experiences two or more of the following signs over a couple of weeks:

Symptoms of depression

- Changes in sleeping patterns (either waking up more at night or needing to sleep more than usual).
- Changes in appetite, for example, loss of interest in food or only being interested in food when it is ’put in front of you’.
- Feeling more ‘teary’ than usual and getting upset about minor matters, for example, running out of toothpaste.
- Feeling even more tired than usual which is not improved by increased sleep or increased relaxation.
- Feeling increasingly more anxious and worried about the situation than the person has felt previously.
- Thinking a lot more negatively than usual, and not being able to limit or restrain these more harmful and negative thoughts.
- Not wanting to see friends and talk to people as much as previously.

Some of the symptoms of anxiety

- Mind becomes hyper-alert.
- Increased sweating.
- Dry mouth and increased thirst.
- Feelings of fear and apprehension that is more than usual.
- Butterflies in the stomach.
- Sleeping difficulties.
- Feeling out of control.
- Feeling as if you are going ‘crazy’.

See the Resources section for more information.

TALKING ABOUT THE DIAGNOSIS

Talking to the person about their diagnosis

Part of the philosophy of *Signposts* is that it is important for the person with dementia to know about their condition in the early stages.

- One of the first questions that a diagnosis of dementia raises is ‘Who needs to be told about the diagnosis?’
- Today it is becoming generally appreciated that, as with any other serious illness, a person with a diagnosis of dementia has a right to know as well as needs to know.
- As many decisions will be required there needs to be an openness to receive and discuss information and ideas so as to learn about the illness and ways to live with it. This openness for the person diagnosed, and for family members, facilitates the best decisions in all areas including legal and financial matters.
- It is important to remember that many people already sense and know that ‘something is wrong’ prior to receiving the diagnosis. This includes both the person with the diagnosis and family members. This can mean that openly addressing the diagnosis is recognising that which may already be felt at some level and can bring a degree of relief.
- If family members are unsure as to what to say, consider discussing this with a counsellor, your general practitioner or some other valued health professional.
- There is also a useful Helpsheet, written specifically for people with dementia, *About You…Talking About the Diagnosis*.

See the Resources section for further details on obtaining Helpsheets and accessing counselling services.

Telling children

People with younger onset dementia are more likely than older people to have younger or adolescent children. The spouse of the person with dementia will inevitably feel worried or concerned about how the illness will impact on children. The following helpful suggestions have been adapted from *Younger People with Dementia*, Alzheimer’s Disease Society, 1996, p25.[2]

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[2] *Younger People with Dementia*, Carer Learning Programme. (1996) Alzheimer’s Disease Society, London.

- Children of any age need to have some basic information about dementia and how it may impact on their parent and their family life.
- Clear, simple and open explanations are beneficial to children. It is also important to provide children with many opportunities to ask questions and to discuss their fears. This may need to be done many times through out the course of the illness.
- False promises that 'things will work out' may only serve to heighten children's fears and apprehension about the future, rather than lessen it.
- It is important to involve children in the care of the person with dementia. However this can not be to the extent that they are given too much responsibility and they are unable to be involved in their own age appropriate activities.
- Younger children may require some reassurance that they have not contributed to the person having developed dementia, or to their unusual behaviour.
- Children and young adults may sometimes feel embarrassed and angered by their parent's unusual behaviour, and may feel uncomfortable about bringing friends home.

Pointers for telling children about the disease

Adapted from: *Younger People with Dementia*, Alzheimer's Disease Society, 1996, p25.[3]

- Explain that dementia is a physical illness that affects parts of the brain slowly over time, and this makes it increasingly difficult for the person to think clearly, to remember or to carry out ordinary day-to-day activities. The behaviour of the person will change and deteriorate and he/she is unable to help or stop this change.
- Their parent or relative is not going to get better as there is no cure at the moment; but there may be one in the future.
- Not only will their parent or relative not get better, but they will slowly be able to do less and less for themselves, and will need more and more help from those who live with them.
- No one is to blame for what has happened to their father/mother or relative.

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[3] *Younger People with Dementia*, Carer Learning Programme. (1996) Alzheimer's Disease Society, London.

- It is not likely that they are of greater risk of developing dementia, however they can see a genetic counsellor to more fully discuss their situation and concerns. Older teenagers and young adults need to be told about this service and given this option.

Alzheimer’s Australia has a range of books written for children of all ages, which can be used to help children understand the changes that are taking place for the person with dementia, and may serve as a useful start to a discussion about the dementia, and how it is impacting, and will impact on family life.

See the Resources section for further reading.

Telling others

‘To tell or not to tell’ friends and neighbours becomes a significant question for the person with the diagnosis and family.

Like any other serious illness, which has been diagnosed, a decision has to be made as to who needs to know about the illness. Who needs to know will change over time. In the early stages a decision may be made to tell those who are most likely to observe symptoms of the disease, such as immediate family, close friends, an employee and work colleagues. As the disease progresses more people will probably notice changes, and family may choose to tell a wider number of friends and acquaintances.

It can sometimes be problematic convincing others that there is a real problem if the person’s symptoms are not readily apparent, especially if the person looks well and healthy and can participate in a social capacity, albeit at a reduced level. Sometimes telling others can assist them understand some of the changes and assist in taking away some of the distress and problems associated with lack of information and silence about the condition.

PLANNING FOR THE FUTURE

Including the person with the diagnosis in decision making

It is important to consider that the person who has been diagnosed needs to be included wherever possible in the important decisions for the present and the future. This will depend to some extent on the capacity and the degree to which they are able to participate in this process. It should not be automatically assumed that the person with dementia does not have the capacity or insight to participate in decision making.

In the early stages of the illness the person may have some very clear ideas about what they want to happen in the future.

It is imperative to take control of the legal and financial situation as soon as possible. This can help to avoid difficulties as the illness progresses.

Some important considerations include:

- Deciding about future employment.
- Planning for the financial future.

- Organising banking systems.
- Finalising legal arrangements.
- Living arrangements.
- Considering future lifestyle decisions.

THERE IS A NEED TO ENSURE THE FOLLOWING ARE IN PLACE:

- An up to date will.
- An Enduring Power of Attorney (Power of Attorney alone is insufficient when the person loses capacity to make decisions).
- Enduring Guardianship.
- Financial Planning with a financial advisor.

See enclosed Helpsheet for further information

The work place

If the person diagnosed with dementia is still employed, their work situation needs re-assessment, reviewing and planning for the future. Those people with financial commitments and families to support need to identify options, and plan accordingly.

If the person is working, consideration should be given to the following:

- Does the employer know the situation?
- Will the employer make provisions to enable the person to remain in the job so that contributions to their superannuation can continue for as long as possible?
- Is it appropriate for the person to remain working?
- Is an advocate (such as Trade Union representative or personnel officer or someone trusted by all parties) available for the person with dementia to liaise with the employer?
- If the person with dementia is not employed, are they claiming all the benefits for which they are entitled?
- If the person is self-employed, what parts of the job are they still able to do? In what aspects of the job will they need assistance? Are they able to manage the financial aspects of the job? How will they wind up the business? Where will they direct their existing clients/customers? If this is not possible, or the choice is not to finish the business, how can the work be continued?

It is important to discuss these issues with the person and to seek their views on what they would like to see happen.

What rights does the person have to stay in their job?

- There is no employment law that specifically deals with younger onset dementia and the workplace. People who believe they have been discriminated against may wish to seek legal advice.
- Employers should not, upon notification of dementia, respond by automatic dismissal or retirement against the person's wishes. The personnel officer or advocate needs to be involved at an early stage to help negotiate with the employer.
- This is a complex area and it is advisable to discuss the situation with a variety of people. For example, a General Practitioner, another health professional, solicitor, trusted colleagues.

Does the carer need to give up their work?

This will depend on the carer's situation. Some carers feel that the shock and the grief experienced on learning of the diagnosis is such that they do not have the energy or resources to continue working. Others have chosen to continue working as it provided a sense of having a life outside the caring role. For others it is a financial necessity to remain working. If uncertain about decision making on this issue, counselling may assist.

Benefits available

If the person with dementia is no longer in employment, the Financial Information Officer at Centrelink will advise about eligibility for financial assistance.

It is important to be aware that there is financial assistance for carers of people with dementia.

Financial planning

- Australian Securities and Investments Commission (ASIC) and the Financial Planning Association (FPA) have produced a useful booklet called *Don't Kiss Your Money Goodbye* to assist people to choose financial planning services, a copy of which can be obtained by contacting either organisation. Contact phone numbers appear at the end of this section. The FPA also publishes a directory of their Principal Members in a booklet format.
- Most banks also offer the services of a financial planner.
- Centrelink's Financial Information Service.

Helpful contacts are listed in the Resources section.

Legal arrangements in the early stages of dementia

If unsure as to whether what has been planned and is in place is sufficient or not, seek further legal advice.

Enduring Guardianship

- The Guardianship Act (NSW 1997) provides the opportunity for people affected by dementia to appoint an enduring guardian.
- This can be arranged in the early stages of the dementia so that another person can make lifestyle decisions on behalf of the person, if he/she is unable to make these decisions themselves.

These decisions can include:

- Where the person lives. For example, a hostel or nursing home.
- What health care is received. For example, treating doctor, community health care.
- What personal care services are arranged. For example, home support services.
- Subject to the provisions of the Guardianship Act, consent for any minor or major treatments.

An Enduring Guardianship application form needs to be signed by the person appointing the enduring guardian, the person being nominated and an authorised witness (who must be a solicitor, barrister or clerk of the Local Court).

Enduring guardianship does not cover:

- Wills.
- Voting rights.
- Consent to marriage.
- Managing finances.
- Overriding the person's objections to medical treatment.

The person with dementia can appoint an enduring guardian, but they must have the capacity to understand what they are doing.

Further information about Enduring Guardianship can be obtained by contacting either the Dementia Helpline, or the Guardianship Tribunal.

Advanced health care directives

- This is a document by which a person gives instructions about future health care. It comes into effect only when the person is no longer capable of making their own decisions. An example of this is whether or not the person chooses to have a life support machine switched off, and under what circumstances.
- In NSW, advanced health care directives are not backed by legislation, unless they form part of the appointment of an enduring guardian.

Obtaining legal advice

This can be obtained from the following services:

- Community Legal Centres – free or at low cost.
- Private solicitors.
- The Public Trustee.
- Chamber Magistrates – at most local courts.

Living arrangements

In the early stages of dementia, usually the best arrangement is for the person to continue living in their own home. This is because the person's home is usually the place that is most familiar to them, and can offer significant environmental support. It may be helpful to change or modify the layout of furniture, appliances or amenities to make it easier for managing at home safely. As the dementia progresses other changes may need to be made to take into account the person's changing needs. For example, putting picture signs on doors to remind the person of the room's function.

For further information about creating an environment that is optimal for the person with dementia, see our range of Helpsheets relating to *The Environment and Dementia*.

Social activities for the person with dementia

Where possible, the person with dementia is to be encouraged to continue with activities, he/she has found enjoyable and interesting. If it becomes more difficult to continue with these activities, consider finding a volunteer, through a local municipal council community services department or church group. The volunteer could assist and accompany the person in continuing with these activities.

Some regional areas provide Day Centre activities.

ⓘ Contact Dementia Helpline or Regional Dementia Advisor (listed in the Resources section) for further details.

Getting a break – using respite care

Caring for a person with dementia can be a daunting and sometimes overwhelming responsibility. It is useful for the carer to have a break from these responsibilities, to have a rest, go out, attend to business or go on a holiday. Many carers find that a regular break allows them to recharge and avoid ‘carer burnout’. Others continue to work and find respite care to be valuable. It usually has the secondary effect of providing the person with dementia the opportunity to socialize and meet other people. In rural NSW, finding and using these services can be difficult but there will be some available.

To find out what respite options are available contact the Carer Respite Centre, which has been specifically funded to let you know about what is available. It may also find it helpful to read a copy of the Helpsheet *Making the Most of Respite Care*. Please see the Resources section for more information.

Residential care

As the illness progresses, it may be necessary to consider other options for caring for the person outside of their home.

Making the decision to find an alternative form of accommodation is a very difficult decision for the family. If family members are prepared ahead of time the decision will be a little easier. Spending time learning about residential care options before the service is needed can be helpful. Knowing about the services, government policies and costs of residential care beforehand can help families making this decision especially if the decision has to be made quickly.

In the early stages of the disease, the person with dementia may express his/her own wishes as to where they might want to live should it become necessary to move in to residential care. Possible options include hostels, nursing homes and dementia specific units. To access information about Residential Care, contact Aged Care Assessment Team (ACAT), your General Practitioner, the Dementia Helpline or Regional Dementia Advisor.

For further information about deciding on residential care, please see the range of Helpsheets relating to *Residential Care and Dementia*. For information about how to obtain a copy of the Helpsheets, please see the Resources section.

RESOURCES TO ASSIST

ALZHEIMER'S AUSTRALIA NSW

Information

An extensive library provides a range of journals, videos, books and articles. These can be accessed by contacting us. The librarian will mail items to members across NSW.

Contacting Alzheimer's Australia NSW and the Library & Information Service

Alzheimer's Australia NSW
PO Box 6042
North Ryde NSW 1670
Telephone: 02 9805 0100 (reception)
Fax: 02 9805 1665
Telephone: 02 9888 4218 (Librarian)
Email: library@alznsw.asn.au
Website: www.alzheimers.org.au

A range of specialist books are available to buy.

Helpsheets, provided free of charge to carers, contain information on many aspects of dementia care.

Free Dementia Helpline 1800 639 331

Professional and trained volunteer counsellors provide information about dementia, listen to and discuss concerns people may have about dementia and its impact on their future. They can put people in contact with their nearest Dementia Regional Advisor, support groups and community services.

Counselling

It is not unusual for family carers to find the diagnosis of dementia overwhelming. Many newly diagnosed people and their family carers find it beneficial to discuss their situation with a professional counsellor. A counsellor will provide a safe, professional and confidential environment to unburden thoughts and feelings, which may be difficult to talk about with relatives or friends.

Depending on the persons needs at the time, counselling sessions can take place either over the telephone or face to face.

Dementia Regional Advisors

Dementia Regional Advisors can provide information, counselling and advice and are available in many rural areas.

Armidale	Community Health Centre	Telephone: 6776 4851
Broken Hill	Far West Area Health Service	Telephone: 08 8080 1476
Coffs Harbour	Mid North Coast Aged Care Assessment Team	Telephone: 6659 9700
Dubbo	Lourdes Hospital	Telephone: 6941 8596 or 6841 8509
Gosford	Aged Care Assessment Team	Telephone: 4320 2644
Griffith	Home Care Service	Telephone: 6964 1166
Lismore	St Vincent’s Hospital	Telephone: 6623 3313
Orange	Community Health Centre	Telephone: 6393 3507
Wagga Wagga	The Forest Centre	Telephone: 6923 2195
Wollongong	Carunya Day Respite Centre	Telephone: 4297 1011

For further information about counselling services in your area contact the Dementia Helpline 1800 639 331 (free call).

Support Groups

There are over 170 support groups meeting regularly throughout NSW. These are available for carers to attend to share information, provide mutual support, engage in problem solving and gain friendship. A group offers members the opportunities to share their stories and experiences on their journey with dementia. At the same time it serves to encourage appropriate decision-making and self-care for the carer. Group members are able to talk about their concerns at the level at which they are comfortable. The emphasis in the groups is on encouragement and support.

These groups usually meet monthly in a local convenient venue for a couple of hours. Most group leaders are health professionals, while some are family carers or volunteers from the community.

The Dementia Helpline 1800 639 331 (free call), can provide information about a range of dementia specific and generic support groups across NSW, and provide contact details about those which are closest to them.

Living with Memory Loss Program

Now being offered in some rural areas, this program is designed for people at the time of diagnosis or as soon as possible afterwards. This program is a seven-week psycho-educational and support program for people living with early stage dementia and their families/carers, and offers the opportunity for talking about the impact of the disease on both the carer and the person diagnosed. Other relevant information is covered including ideas for self-care, problem solving and managing financial and legal affairs.

Helpsheets

The Dementia Helpline 1800 639 3311 (free call) and Website: www.alzheimers.org.au can provide information on these concise information sheets covering a wide range of topics associated with dementia. The information sheets are available free of charge to carers.

A set of the Helpsheets is available to health professionals at a small cost.

Family Carer Education

Alzheimer's Australia NSW conducts free seminars and discussion groups designed to assist family carers. A calendar of events is available by ringing the Dementia Helpline. In rural areas, a Dementia Regional Advisor will have information about programs that are being conducted locally.

ALZHEIMER'S AUSTRALIA

The National Dementia Behaviour Advisory Service 1300 366 448 (Free Call)

This is a National telephone advisory service for respite care staff and carers, who are concerned about the behaviours of people with dementia. Carers and respite care staff can use this service.

The service provides confidential and comprehensive advice 24 hours a day, 7 days a week.

AGED CARE ASSESSMENT TEAMS (ACAT)

The regional ACAT can assist people to obtain a range of Commonwealth funded services to help them to continue living in their own homes. If the person has difficulty in remaining in their own home, the ACAT can provide advice, information and assessment to enter a residential care facility such as a nursing home or hostel.

The ACAT is usually based at a hospital, geriatric centre or community centre. The staff can see the person with dementia, either in their own home or in hospital. The ACAT might include doctor, nurse, social worker, occupational therapist or physiotherapist. These teams will provide assistance to people with younger onset dementia.

Making contact with Aged Care Assessment Team

Your doctor can refer the person with dementia to the nearest ACAT. Information on the nearest ACAT is also available by contacting The Aged Care National Information Line on 1800 500 853 (free call).

CARERS ASSOCIATIONS

In each State and Territory there is a Carers Association working to bring the needs and concerns of carers to the attention of the community as a whole including government makers, health professionals and service providers.

Each Carer Association operates independently and offers a range of services and support. Carers NSW also provides information about generic support groups: groups that are open to carers of people with a range of disabilities, including dementia.

For information and support carers can call free

NSW	1800 242 636	www.carers.asn.au
ACT	1800 242 636	www.carers.asn.au
Tasmania	1800 242 636	www.carers.asn.au
South Australia	1800 242 636	www.carers.asn.au
Victoria	1800 242 636	www.carers.asn.au
Northern Territory	1800 242 636	www.carers.asn.au
Western Australia	1800 242 636	www.carers.asn.au
Queensland	1800 242 636	www.carers.asn.au

CARER RESPITE CENTRES

Respite services offer a respite or break from the work of caring for someone who is unwell. It may be for a few hours, a night or a few weeks. Respite is an important way of relieving the stress of being a carer, and looking after one’s own health and well being. Respite Care Centres are Commonwealth funded, and can provide carers with:

- Information about respite services.
- Help to organise respite.
- After hours respite in times of crisis or emergency.
- Access to respite in nursing homes or hostels.
- Someone to ‘lend an ear’ to listen.
- Assistance with the cost of respite when needed.
- Referral to other services for on-going support.

There are 17 Respite Care Centres across NSW. For information about the closest centre, telephone 1800 059 059 (free call).

COMMONWEALTH CARELINK CENTRES

These centres provide information about the range of services available in your community and how to contact them. These services include:

- Household help.
- Personal and nursing care.
- Meal services.
- Home modification and maintenance.
- Transport.
- Disability services.
- Respite care.
- Day care and therapy centers.
- Continence assistance.
- Support groups.
- Community Aged Care Packages.
- A range of other health services such as podiatry and physiotherapy.

Also:

- Specific services for dementia.
- Whether there are any costs associated with the services.
- Aged Care Assessment Services.

For information about the nearest Commonwealth Carelink Centre,
telephone 1800 052 222 (free call).

COUNSELLING SERVICES

- See Alzheimer’s Australia NSW.
- See Carers NSW.
- Lifeline 24 hour counselling. Lifeline can be contacted on 13 1114.
- Mental Health Information and Referral Service. This service can be contacted by phoning 1800 674 200 (free call).

DEPRESSION AND ANXIETY

- See Alzheimer’s Australia NSW.
- See Carers NSW.
- See Counselling Services.
- See Websites.

FINANCIAL PLANNING INFORMATION AND ASSISTANCE

- Financial Planning Association (FPA) Telephone: 1800 626 393 (free call)
  Website: www.fpa.asn.au
- Australian Securities and Investments Commission (ASIC)
  Telephone:1300 300 630 (free call)
- Centrelink For appointments with Financial Information Service, telephone 132 300.
  For seminar bookings and information telephone 136 357
  Website: www.centrelink.gov.au

GUARDIANSHIP AND FINANCIAL MANAGEMENT ISSUES

Guardianship Tribunal

The Guardianship Tribunal can assist when informal arrangements are not working for adults who are incapable of making lifestyle or financial decisions for themselves. The Tribunal can do this if there are disagreements with decisions that are being made on behalf of the person with dementia, or if there are concerns that the person with dementia is in need of protection from abuse, exploitation or an unsafe situation. It is usually the option of last resort. The Guardianship Tribunal can appoint guardians and financial managers and give consent for medical and dental treatments. Telephone:(02) 9555 8500 (enquiries) or 1800 463 825 (free call) Website: www.gt.nsw.gov.au

Office of the Public Guardian

This is a separate body from the Guardianship Tribunal. When appointed by the Guardianship Tribunal, The Office of the Public Guardian can make lifestyle decisions about accommodation, medical treatment or community services, when a person lacks the capacity to do so themselves. They do not provide case management services, or provide substitute care. Telephone 02 9265 3184 or 1800 451 510 (free call)

Protective Commissioner

When appointed by the Guardianship Tribunal, the Protective Commissioner acts to protect the assets and legal rights of a person who is not competent to manage these. The Protective Commissioner has the power to facilitate buying or selling a home, provide cash flows to pay bills, make investments, monitor the person’s quality of life, supervise and support private managers. It is a self-funded organisation, so charges a fee for service. Telephone: 02 9265 3131

GROUPS

- ⓘ See Alzheimer’s Australia NSW – Support Groups and Living With Memory Loss Program.
- ⓘ See Carers NSW.
- ⓘ See Community Services ‘Commonwealth Carelink Centres’.

INFORMATION ABOUT DEMENTIA, MENTAL HEALTH AND RESOURCES AVAILABLE

- ⓘ See Alzheimer’s Australia NSW.
- ⓘ See Websites.

REGIONAL DEMENTIA ADVISORS

- ⓘ See Alzheimer’s Australia NSW ‘Counselling’.

WEBSITES

Dementia

ⓘ www.alzheimers.org.au
Alzheimer's Australia

ⓘ www.dasninternational.org/
DASN Dementia Advocacy and Support Network. 'A worldwide organisation by and for those diagnosed with dementia working together to improve our quality of life.' Access to chat rooms.

Mental Health

ⓘ www.beyondblue.org.au
A website with information, personal stories etc for people with depression and their families.

ⓘ www.depressioNet.com.au
A website with information, personal stories, etc for people with depression and their families.

ⓘ www.health.nsw.gov.au
The NSW Department of Health Web site. Information on everything to do with health.

ⓘ www.mentalhelp.net
The webs largest guide to online resources on mental health topics. It has extensive links.

Other Helpful Websites

ⓘ www.mja.com.au
An invaluable resource published by the Medical Journal of Australia.

ⓘ www.mydr.com.au
An Australian site providing comprehensive information on a range of health topics.

ⓘ www.carers.asn.au
Carers Association NSW

Early Onset Dementia

ⓘ www.alzheimers.org.au
Alzheimer's Australia

ⓘ http://dementia.ion.ucl.ac.uk/candid
This is the web site for C.A.N.D.I.D. (Counselling And Diagnosis in Dementia). It was developed to deal with the special issues that young onset dementia victims face. It is maintained by the National Hospital for Neurology and Neurosurgery in Queens Square London.

COMPLAINTS

What do you do if you are unhappy with a service?

If you are unhappy with a service you have choices in the way the situation can be resolved. Improvement of service delivery helps all service users and you have the right to receive optimal services and advocate for people with dementia. You have several options in acting upon your dissatisfaction:

- Gather information about the complaint, if necessary.
- Notify the service provider.
- Meet with service provider in an attempt to resolve the situation, organise a support person to accompany you.
- Leave the organisation.
- Make a formal complaint.

Formal complaints can be made through the following organisations

Aged Care Complaint Resolution Scheme

Telephone: 1800 550 552 (free call) or write to GPO BOX 9848 Sydney NSW.

The scheme is:

- A free service.
- Run by the Commonwealth Government.
- Available to anyone who wants to make a complaint about any aspect of an aged care service.

This includes residents of nursing homes and hostels and their families, staff, people receiving community aged care packages or anyone else.

It offers confidentiality and anonymity if required.

If you are uncomfortable discussing the problem directly with the service provider you can contact independent Complaints Resolution Scheme.

Patient Support Office

Telephone: Health Care Complaints Commission for your local office 1800 043 159 (free call in NSW). TTY for the hearing impaired 02 9219 7555.

The Patient Support Office helps dissatisfied persons by providing a trained Patient Support Officer employed by the Health Care Complaints Commission to independently assist with concerns about all health service providers.

These range from public and private hospitals and health centres, to the individual actions of a particular professional, therapist and any other person or organisation that provides a health service.

The Private Health Care Branch of the NSW Department of Health

This branch has a Complaints Team that manages complaints about Nursing Homes, Private Hospitals and Day Procedure Centres.

Contact: Complaints Coordinator, Private Health Care Branch, NSW Department of Health, Locked Mail Bag 961, North Sydney 2059.
Telephone: 02 9816 0482 or 1800 809 590 (free call) Fax: 02 9816 0243

People can complain about the care provided, the standard of food, cleaning and laundry, condition of the buildings or any other aspect of service delivery. Complaints about individuals are referred onto The Health Care Complaints committee.

Complaints about the actions of Guardianship Tribunal staff or Tribunal Members

You can complain about the actions of the Guardianship Tribunal or a Tribunal member(s). You can also appeal some decisions of the tribunal. Telephone: 1800 463 928 (free call) or 02 9555 8500 or write to the Registrar of the Guardianship Tribunal, Locked Bag no.9, Balmain NSW 2041.

The Private Guardian Support Unit

The Private Guardian Support Unit provides information and support to people legally appointed as a guardian in NSW.

The unit is separate to the Guardianship Tribunal and is funded and staffed by the Office of the Public Guardian. Telephone: 1800 451 510 or 02 9265 1441
Fax: 02 9283 2645 or write to: PO Box A231, Sydney South NSW 1235.

Community Legal Centres in NSW

Provide free legal advice, casework assistance, referral and information and are independent, non-profit making organisations.

There are 36 centres in NSW. They provide general legal services and also specialise in specific areas of law including disability rights. You are eligible if you cannot afford the services of a private solicitor. Contact: NSW Community Secretariat on 02 9318 2355.

NOTES


COUNSELLING
ADVICE
DECISION MAKING
GROUP PROGRAMS
CARE
INFORMATION
FINANCES

Alzheimer’s
Australia NSW
Living with dementia