CONSUMER REFERENCE GROUPS CONVERSATIONS 2012 - 2015

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ALZHEIMER’S AUSTRALIA SA
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**Consumer Reference Groups Conversations 2012-2015**

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The National Dementia Helpline
1800 100 500
(NDH is an Australian Government initiative)
INTRODUCTION: VOICES AND VIEWS

Alzheimer’s Australia SA is committed to making sure that the voices of people living with dementia, their families and carers across South Australia are heard and that its policies and programs reflect the needs of South Australia’s dementia consumers.

This report consolidates the conversations - the voices and the views - of its consumer reference groups for the period May 2012 to July 2015.

As part of its strategic engagement with people living with dementia, their carers and the agencies providing services for them, Alzheimer’s Australia SA has a number of consumer reference advisory groups that play an ongoing role through regular discussions and by making comment on issues as they arise.

The consumer reference groups draw on the skills, experience and knowledge of a cross section of people. They provide a range of views and perspectives on issues affecting people living with dementia, their families and carers. They also provide feedback on, and recommendations for, Alzheimer’s Australia SA’s policy, service, training and research initiatives.

Alzheimer’s Australia SA’s consumer reference groups include:

- The Alzheimer’s Consumers Alliance SA: established in 2012, including people living with dementia, family carers and representatives from peak not for profits and government agencies.
- The Residential Care Consumers Reference Group: established in 2013, including carers of people in residential care.
- The Younger Onset Dementia Consumers Reference Group: established in 2013, including people with younger onset dementia and their carers.

There are forty one members of these groups, including eight people with dementia, twenty three carers and ten representatives from service providers in the government and not for profit sectors.

Over the time covered by this report, there have been thirty six meetings of the consumer reference advisory groups; twenty of the Alzheimer’s Consumers Alliance SA and eight each for the Residential Care and Younger Onset Dementia Consumers Reference Groups.

Alzheimer’s Australia SA acknowledges the continuing contribution of these consumer representatives.
REGARD FOR THE PERSON WITH DEMENTIA

Individual Dignity

Every person’s experience is different. It depends on communication, the signs, the ability to define the particular care for the person with dementia: walking in the person with dementia’s shoes.

Maintain the dignity of the individual. People living with dementia still deserve treatment, respect and care.

Treat people with dementia with care.

Provide respect for the person with dementia.

Express concern for the person with dementia: be re-assuring.

People talk to the carer not the person with dementia.

Communication and Behaviour

People with dementia should not be talked down to.

Making speech understandable.

How to communicate with someone with dementia?

Learn the body language! It is often the only communication, for example, anxiety, pain.

How to respond to someone who is exhibiting difficult / challenging behaviour?

Don’t call ‘different’ behaviour ‘bad’ behaviour. ‘Bad’ behaviour is usually ‘bad handling’ of a person.

Communication by the Person with Dementia

People with dementia need time to compute questions they cannot answer immediately.

Ability to write and being able to complete sentences.

Phone calls, taking messages, communicating with others; taking a while to find the right words.

Language is there but is not necessarily able to be put into context.

The person with dementia cannot necessarily make informed decisions.

Meaningful Life

Creating a meaningful life for the person with dementia whilst also maintaining my life and my family life.

There is a restriction of lifestyle.

There is emotional loneliness.

Giving People With Dementia a Voice

There is not enough voice for the people living with dementia.

There needs to be more people living with dementia presenting during Dementia Awareness Week. Not having people living with dementia as speakers increases the stigma. There needs to be a change in the thinking. At public events there should be people living with dementia speaking.

Full equity and inclusion for people living with younger onset dementia – the voice of people with dementia at conferences, events, forums etc globally is usually missing.
AWARENESS

Stigma

Stigma still exists.

There will be stigma attached to dementia until the community is confronted with the issues they don’t want to know but need to know.

With stigma people are frightened about what to say: encourage people to talk normally. An issue is how facilities discuss dementia, how they deal with it.

We need dementia champions to help overcome stigma.

Friends stop coming because they “can’t cope anymore”.

Creating Awareness

One push is that people living with dementia move in a different world. The world, generally, is growing at a different speed. Other people get irate at people living with dementia because they don’t understand. If you say ‘dementia’ to people you still get a pint of ignorance. There is less knowledge than about cancer. This will continue until the spread of basic information about dementia.

Ads need to be about people with dementia being included in community life.

We need to be in the ears of Practice Nurses.

Have opportunities for learning and growth about dementia and the issues surrounding it through the media.

One area that is missing is with the general public. There are various levels of services available but most people don’t know what dementia is. This ties in with creating dementia friendly communities.

Semantic dementia: there is a lack of understanding with other people that things are not always what was expected.

There is a lot that has not changed whilst a lot has changed over the last few years: maybe 50/50. People are more conscious of dementia these days. Talking about it these days.

We need HACC drivers who understand dementia, that is, who have an understanding of the people they are dealing with. We need education for these people.

At the airport, if there could be something on information screens about the needs of people living with dementia. A carer is not allowed to wait for the person with dementia coming through customs.

There is a commitment by the RAA to have staff on the road aware of dementia.

Get training at retail outlets.

A good place to start is at a major food store chain training staff on the “Who, what, when, where, why.”

In Schools

Start with the kids at school. The grandchildren ask questions about the person living with dementia. Kids accept things if you explain it.

Place health and personal care in dementia in the school curriculum.

Changing attitudes when people are young: helping to raise awareness from an early age through projects in schools.

Rural

There is less support and information to country areas.

Linking people regionally is required. People with understanding will access services.

We moved to a small country town. Support with the public for people with dementia has taken a long time to sink in, particularly for those who do not have a family member.

Dementia has got to be given the same publicity as cancer. It needs to be really drummed in that dementia is not an old person’s disease.
Diversity

In Aboriginal communities dementia was not recognized or acknowledged. Carers care as part of family, as the normal thing to do, which makes the response by care agencies difficult because of the minimal number that identified as carers.

Issues include denial issues and no help from family, lack of Indigenous services and lack of knowledge about services.

Younger Onset Dementia

Creating awareness in the community of younger onset dementia.

Awareness of younger onset dementia will help with acceptance, for example, the same acceptance as another illness.

I feel like I am selling him out when I introduce him as someone with younger onset dementia because this leads to different interactions by others. Need a TV ad to explain dementia better.

EDUCATION

Education is about getting to the uncommitted: how to make people change, in particular, professionals. Massive cultural change is required.

The priority of education as a whole, which means so many different things, is building awareness of support in the community.

Seeing the carer as a resource.

Education for Professionals

People working with people living with dementia need education: without education nothing will happen.

In early intervention and education is where dollars enter the equation. There is cost saving from early intervention; from educating nurses, doctors: it all starts with doctors.

Better education in dementia for the professionals we have to deal with.

Lack of education about dementia with GPs, nurses, care workers, the public, post graduate and undergraduate courses.

It should be compulsory that every person in aged care be taught in in behaviour and dementia understanding, for example, Cert 3 is industry standard but is not mandatory.

The 6 to 8 week Cert 3 course is inadequate, does not really deal with dementia.

More training for home care workers in understanding people living with dementia.

There is a need to talk to universities about their curriculum, in particular for doctors and nurses, and also to TAFE so dementia has a higher focus in courses.

There should be professional development points per year regarding dementia, particularly in acute and residential settings: making dementia friendly communities a possibility with residential care, acute care and palliative care working together.

GPs

GPs don’t know how to medicate people living with dementia.

Aged Care

There are people who slot into aged care because there is a ‘bucket of work’. They only need registration, not training. The onus is on the employer. There is a need to facilitate rights based training.

There is the importance of dementia training in the aged care sector. There is inconsistency, but to get the consistency facilities need financial resources. The vast majority of employees are care workers. They need dementia champions in their communities.

Need an emphasis on dementia training for anyone in aged care; even if online for fifteen minutes at the specialist level. Training needs to be relevant at any point in time.

Management Attitude

Being dementia friendly comes down to management attitude, leadership, education and supporting staff.

Consumer Involvement

Get community involvement (memory clinic) in education programs to help with early diagnosis, quality care, GPs, hospitals, acute care and support for care workers (personal support workers).
Technology is reaching more people: using DVDs from the Alzheimer’s Australia SA Resource Centre and on line forums and using community resources.

The Message

This is about being human, being part of society. It’s a journey. That is the education message.

We need to move from the myths around debunking an older person’s disease to the reality that living with dementia could happen to all of us.

Provide education to medical services regarding the behaviour of people living with dementia and appropriate restraint. The medical system needs more understanding.

Have a rights based education and training framework more than a treatment based framework.

We need to make a bigger gaps between mental health and dementia. People with dementia are on a different crusade.

Resources

Use videos of people living with dementia talking about their experiences as material in schools.

TIMELY DIAGNOSIS

What are the triggers leading to diagnosis?

Diagnosis needs to be navigated. Appropriate diagnosis helps people make decisions about their life. There is the perception that to change the system is too hard.

A timely diagnosis would give families more time to understand and prepare for the future.

There is changing diagnosis through the stages of the disease.

There are huge expectations on GPs. This requires cultural change and more support from Medicare through improved forms, numbers and greater financial incentives.

Receiving a diagnosis should be made in calmness and not horror. There are supports in the community, helping people live positively with dementia.

Limits and Barriers to Diagnosis

There are concerns about getting diagnoses at local regional hospitals where staff were not positive or supportive.

Barriers to timely diagnosis include the person with dementia hiding things, people not picking up on even trivial signs, GPs not being as aware as they could be and long waiting times to see GPs and specialists.

The My Aged Care Gateway will be unsatisfactory due to the limits of information and ‘assessment’ on the telephone. This also gets back to effective navigation assistance.
Diversity

There are major issues with people from cultural and linguistically diverse backgrounds. For example, 40% of TQEH clinic clients do not speak English. Cultural responses include ‘shame’, not wanting a diagnosis, not wanting government ‘interference’, the expectation of children ‘looking after mum and dad’. There is a lack of culturally specific health centres.

A lot of people in the Chinese community are not diagnosed because of community attitude. There was a lot of work to nurture community members who are caring 24/7 but often they don’t ask for help.

Younger Onset Dementia

Barriers to timely diagnosis for people living with younger onset dementia include not looking at a younger person as having dementia.

GP’s can’t get anyone in Adelaide to see people living with younger onset dementia.

Following Diagnosis

Getting the diagnosis right would enable the treatment of problems at the doctor level.

After diagnosis what are the opportunities for the range of services for partners, carers and families?

As soon as someone is diagnosed there is a wariness about accepting the person with dementia for rehabilitation because of a perceived lack of day to day memory. The professionals cannot see how the person with dementia could be rehabilitated.

It is helpful to have a support group that knows what they are doing, including the chemist, GP and friends.

CARE MANAGEMENT: NAVIGATION SUPPORT

The hardest part was before the navigation. How does the consumer know there is an issue before going to the next level of navigating services?

We went to the GP after the diagnosis and was told, “Oh, I could have told you that years ago!” When asked why not, the GP said it was confidential.

So how does one find out about these things, trying to work out what was going on and how to cope with the next step?

That is the most important thing – where to start!

Issues

Navigation is still a problem.

Navigation is always going to be a problem.

It is too hard to manoeuvre a very complicated system. It is very confusing.

Working out what is controlled by one organisation is difficult: there are implications for consumer directed care.

Start navigation support at the beginning. Have numbers of dementia link workers and educate assessment workers.

When given a diagnosis the consumer should not be left to deal with things on their own. They should be sat with someone for counselling and information. The first time the consumer has a conversation, the consumer doesn’t take anything in because they are so numb.

How do people without support navigate?

The dementia journey is like snakes and ladders with carers always looking for the ladders.

Navigating the pathways through services needs to be transparent and painless.

There was considerable time researching and reading. Navigating through the paperwork was a nightmare.

Where consumers are in the dementia journey determines what is important for them. Broaden navigation so it takes place from the beginning to the end of the dementia journey.
Resources of Assistance

We need a world class one stop shop in dementia (information, referral, including specialists).

In Finland, on diagnosis, people are linked to services straight away.

Role of GPs: they are focused on the immediate issue and the attitude is that the signs of dementia can wait.

Medicare Locals were looking at collaboration with primary health. There were pilots with GP practices investigating the uptake of referrals.

The National Dementia Helpline is terrific, referring people to their local worker.

Dementia Link Workers connect with the person living with dementia to provide information.

Part of the strategy is to get people living with dementia contacting Alzheimer’s Australia SA.

Primary care providers and GPs have a part to play in getting a consumer to the diagnosis. Then the GP needs to navigate well. Is there material in GPs’ waiting rooms, libraries and councils?

Would someone, for example a link worker, being placed within the memory clinic two days a week be useful? Yes it would.

Since we have breast cancer nurses then why not dementia nurses?

**Diversity**

The new My Aged Care gateway will be a massive problem for people from Culturally and Linguistically Diverse and Aboriginal communities. These people will be referred to mainstream agencies and their back story will be missed.

If receiving support from two agencies, for example from the Department of Health and Ageing and from Centrelink, it can be hard to understand what is going on, particularly if from Culturally and Linguistically Diverse communities.

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**COMMUNITY CARE**

**SERVICES**

*Empathy on behalf of the service is what is required.*

Reduced income tested fees.

One size does not fit all. We need public education about this. The person with dementia gets used to one person and one program but they might only be there for six months. There is no continuity. For example different people coming in to shower the person living with dementia.

Packages are inflexible and inadequate, for example, EACHD has a long waiting list.

There needs to be more information and support for rehabilitation, non-pharmacological interventions.

The My Aged Care gateway is flawed because of language and “how can people be assessed over the phone?”

Rural

What happens to people living in the country?

In the country there is often not someone just around the corner so the Alzheimer’s Australia SA support worker in the Limestone Coast is really valuable.

For those at a distance from services talking to someone on line, for example using Skype, would be helpful.

Transport is an issue, especially for those not on a bus route.

**Pop-up Brain Health Hubs**

Shopping centre hubs would be a win-win to offer something to shoppers.

**Younger Onset Dementia**

There is a lack of knowledge that younger onset funding is now coming from the disability area. Younger onset issues need to be a priority for disability services.
There have been contradictory messages about younger onset dementia going to aged care or disability, but how is that to be translated into practice?

Creating meaningful activity for young carers of people with younger onset dementia. One organisation can’t cater for everyone. Need a mechanism for organisations to work together to provide services and support, to meet the needs by providing inclusive services.

**Key Worker Program**

There is a lot to do with people with younger onset dementia. The Key Worker program is essential, particularly if the person with dementia is on their own. There is a need for a continuum from the younger onset dementia key worker to the dementia link worker without a gap. The contact needs to be kept up.

One member stated that they had to work hard to get a key worker, “I got what I got because I was connected.”

The aged care reforms are changing the types of services being funded. Volunteers will have to do more. There will be significant impact on GPs. We still do not know the full impact of the aged care/acute care changes.

**Young Carers**

There is a need for support groups for young people (young carers of people with younger onset dementia in particular): do fun stuff but have a serious intent.

**Counselling**

The need for counselling remains strong.

There is a need for introducing grief counselling. Grief is not just a once off event but is constant change and results in the loss of functions. This is particularly important post-caring and/or following the death of the person with dementia.

**Diversity**

Including socially and culturally diversity groups is important, including Culturally And Linguistically Diverse communities, Aboriginal and Torres Strait Islander communities, people living with younger onset dementia and people living with rural and remote areas.

Culturally And Linguistically Diverse sub cultural barriers include language barriers, and no or limited understanding of systems. A number do not seek support because they see caring as there duty as a family member. Some Culturally and Linguistically Diverse communities don’t even have a word for dementia. Getting community members into residential care is another hurdle.

**RESPITE**

Getting respite comes back to timely diagnosis and navigation support.

There is a new generation coming through with a new perspective on respite.

There is still confusion about ‘who is the client?’, that respite for the carer must be seen as separate to consumer directed care for the person living with dementia.

Carers worry about their spouse when they are in respite.

**Crucial**

*Carer respite is so important.*

Meaningful support should be first class to enable a much happier life.

Respite is absolutely critical for the carer: carers need Monday to Sunday services, arguably 24/7, not Monday to Friday services.

**Limited / Appropriateness?**

High care and respite for people with younger onset dementia are virtually non-existent. Without support, respite can be expensive, for example, $2,000 for four days. Under Consumer Directed Care respite could cost $600 for 24 hours or $1200 for two nights. What are the implications for Disability Care (NDIS)? Would there be more service providers with more competition?

We need more respite facilities especially in country areas.

So many carers don’t have or take respite because it is not appropriate.

Appropriate community care includes respite.

Putting more money into respite will not count if facilities / or beds are not there.
From 2015 centre based day care is to be abolished: who then will provide this service?

Respite is a huge issue. Where do people go to for appropriate respite for the person living with dementia, for the carer / family member at the different stages of the disease?

There are a number of programs in a number of areas in dementia but carers are still trying to access a very limited amount of available respite. There has been very limited progress in this area.

**Younger Onset Dementia**

There are not enough available age appropriate respite services for younger onset dementia. Only Norman House is suitable in all of Adelaide.

In 2011, of nineteen respite centres on a respite centre list, only one was appropriate for people living with younger onset dementia.

Aged care facilities are finding providing respite for people living with younger onset dementia as increasingly difficult, as too hard, too complicated, with too much paperwork.

**A Journey**

*Respite needs is a journey through at-home (community) care, day care and then residential care. There needs to be a smooth transition through this journey.*

**Other**

Respite should ‘look like home’ to reduce the stigma.

By the time the carer takes them and picks them up there is not a great deal of time left for the carer.

We are accessing services now because of the help I’ve done for all those years; you don’t have to do everything by yourself.

Two different sorts of respite are needed for the person living with dementia and the carer.

Can a person buy respite under consumer directed care and do they know they can buy respite?

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**CARING FOR CARERS**

Carers are the real heroes.

*There needs to be a lot more caring for carers, particularly for those who have a loved one in residential care. Some areas are proceeding in this respect.*

Government policy is about keeping people in the community so the carer’s day is harder and longer.

Carers learn as you go. They do not necessarily know the stages of dementia or what to expect. Families give up and put the person into care.

Getting information is vital.

Carers are still floundering.

Males, being task oriented, could cope with the right training and packages.

Carers want not pity but understanding.

After placing the person with dementia into residential care ‘relinquished’ carers need ongoing support. Often getting the preferred residential care option was difficult. One carer had formed a small family group in the facility.

**Re-engagement**

*I never gave up on ‘me’. I engineered hanging onto my interests.*

What’s hard to come to terms with is the partner not being there. The GP was very emphatic; “you have to get another life”.

People talk about experiencing coping with the guilt of not seeing the person with dementia every day, of getting their own life back following giving up most if not all of the previous life to care for the person with dementia.

We still meet with people we met at a weekend away. Life had really changed. The shutters can go up in the family, at Rotary, sporting clubs, the church, so I can talk to these people about what is happening. People then come up and share their experiences.
There is a realization of all the time she now has from when she used to see her husband.

Keep other people informed about what was happening with the carer. This helped to re-engage.

Re-engaging: taking on new interests, in particular visiting family interstate following the death of the partner.

Re-engagement of activities or create new ones.

**Carer Emotions**

*I was neglecting the rest of the family to an extent, not feeling like a couple, feeling like being unable to go to things and feeling that grandchildren visiting would put them at risk.*

Hearing about what other people were feeling was helpful. You need to look after yourself first; re-charging batteries: to be able to travel for a month and not feel guilty about it.

Guilt uses energy that could be better used positively.

I did not feel guilty about putting the person with dementia into care because they would be getting better care.

You feel guilty if doing things and think “S/he would love to be doing this.”

It is important to have a positive attitude. Be aware of how the mind impacts on the bodily functions.

Recognition in hospital: you have to force yourself to be pleasant, chatty and friendly.

**Young Carers**

The role of children in caring: this is the next arm of care, particularly for people living with younger onset dementia. There is opportunity for links with Headspace.

Grandchildren of people living with dementia need support too. They are coping as best they can: “I just want to remember nanna as she was”.

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**DRIVING AND DEMENTIA**

Getting funding for driving assessments as a core service will result in less accidents etc.

The driving and dementia experience is a volatile environment.

Insurance cover for people with dementia? Different companies have different insurance products.

OT assessment is medically based whilst Department of Transport assessment is competency based.

Get in early, that is, on diagnosis. Make driving assessment available, not removing the licence but assessing the impact of dementia on the driving ability and being able to compensate for that.

The loss of licence by people with dementia should be part of community transport plans.

We need more specialised assessment services and driving and health clinics.

GPs a prime target in getting better driving assessment.

What is the criteria expected on the issue of getting (disability) parking permits from Services SA?

**Younger Onset Dementia**

Under 65s need to be able to access community transport services.

Younger onset dementia presents differently from the over 65s including loss of independence.
CONTINUING CARE

HOSPITAL AND MEDICAL CARE

Community Care

More medical care in the home so people don’t have to be taken to hospital for small matters.

More open consultation with doctors that are supervising care.

The family GP sent notes to the GP attending the aged care facility. The coordination of the GPs meant a slight tweaking of the medication. Everyone was happy to be seen by the facility doctor.

Health insurance covers the heart but not the brain. Why not? Dementia is a physical ailment with mental consequences.

Often medication is working against people.

Different drugs given to the same person can work against each other.

A dental appointment was cancelled because the partner was not in a fit state and the carer could not guarantee attendance because of the behaviour. The clinic appreciated the situation. The dentist understood.

Diversity

There are people in the Aboriginal community who are released from hospital care into the community, but they need high care and can become most dangerous to themselves and others.

Acute Care

Acute care needs improvement.

In hospital it is the environment that is a large percentage of why people with dementia act as they do.

We need to come up with answers for quality care for the people who need it.

Staff understanding of the reason family carers might be helping in a hospital setting, for example, toileting, feeding.

Ambulance officers and paramedics have a lot of questions about dementia.

What happens to patients with dementia if they don’t stay in bed?

In hospital he went ‘off beam’ and did not know the carer at all. A change in environment can be very unsettling for people with dementia. In the RAH the Lavender Ladies were great support. In the emergency department there were people who should not have been there, for example, those who were ‘bombed out of their mind’ or aggressive. There should be somewhere else these people can be taken.

Concerns that “there won’t be dementia at the RAH” because TQEH will be facilitating where the ageing will go, but there is no way that the RAH won’t come across people with dementia. Every hospital should be geared up for people with dementia. Alzheimer’s Australia SA needs to have a massive voice in this.

Members were supportive of the use of an identifying symbol in hospitals, for example the one developed in Ballarat now being used in a number of sites. Use of a symbol would indicate that the hospital was working toward creating dementia friendly environments.

Discharge planning needed to be addressed.

There was a need to differentiate patient wellness with just “stitching them up”.

Rural: Younger Onset Dementia

There is a lack of knowledge about younger onset dementia by GPs. Our rural GP is using the carer and the person with dementia as guinea pigs. Also lack of knowledge in psychiatrists and psychologists. One GP stated that my partner was only the second person with younger onset dementia he had met in 30 years of practice.
**THE RESIDENTIAL ENVIRONMENT**

It is about looking after the individual as best you can.

It has been observed that in the last four years more people are entering aged care facilities with aggressive and disturbed behaviour.

Top level people should consider the residents.

Recognising, understanding and supporting the different needs of residents. Residential care seems to have little or no good communication on all levels. They want clients to comply with what they want instead of what the client’s needs are.

Residential care homes should be more ‘in the community’ so that the community sees the situation.

Have a ‘currency’ within nursing homes because people are lost without money.

The use of physical and chemical restraining in all residential care is a concern.

How can private providers possibly make money out of aged care?

He went from one facility to another across the road. It was the same organization and the same management but the care is so different where the majority of staff care and understand. The Nurse Manager calls to have coffee and seek feedback about how things are going and the Enrolled Nurse is on the floor 95% of the time.

The new system of bonds for aged care facilities is proving expensive and putting people off placing their family member into aged care facilities.

Fear of partner going into residential care.

We need appropriate residential care both respite and permanent placement.

**Younger Onset Dementia**

There is the difficulty, even impossibility, of placing people with younger onset dementia in respite and residential care, in particular those with difficult behaviours. There is a lack of appropriateness of younger onset dementia placements; of procedures and processes for assessment of people living with younger onset dementia.

There is nothing in residential care for people living with younger onset dementia in South Australia. The question arises: why isn’t it just easy to build a place for people living with younger onset dementia? People living with younger onset dementia can end up in the mental health system if they have delirium, for example, which is really inappropriate.

I do not want to put my husband in residential care with 80 year olds.

Better care homes for younger onset people who cannot be cared for at home.

A Younger Onset Dementia Key Worker needs to work with facilities to make them younger onset dementia friendly. Aged care facilities are funded by the Commonwealth for the over 65s. NDIS won’t build facilities for people living with younger onset dementia.

Being age aware about younger onset dementia includes:
- Awareness that people with younger onset dementia are physically able.
- Providing age appropriate activities.
- Speaking appropriately, not ‘baby talk’.
- Age appropriate general knowledge: connection with residents.

**Person Centred Care**

*Dignity in Care.*

Empathy.

Management of different behaviours.

Mental health training.

Dementia focussed strategies in practice.

Be trained in holistic framework.

More staff to be relationship oriented.

Need more staff to allow time to give better person centred care.

Having a good document that tells the story of the person with dementia.

Lack of care by some residential staff for clothing and shoes.

Relate care to how they would like to be cared for.
Routines / Activity

The person with dementia is not in a static environment. It is very changeable. There are changes every day; no constancy.

Treat the residents in a manner which will aid the wellbeing of the individual.

Changes in routine will disrupt from what people are used to.

Once continuity stops this is statistically when people start to deteriorate more quickly. This period of deterioration could be much shorter if the facility learnt how to deal with it.

There are only two people from 2.00pm to 9.00pm to calm the agitated. No day is the same.

What percentage of people with dementia in aged care facilities receive oral hygiene, a dental clean? The answer is a very small percentage. It is a person’s right to have the care.

The person with dementia wants to and can play Bridge. Every time the carer leaves he cries.

There needs to be more activities taking into account the background, interests and needs of residents.

More lifestyle care workers so activities are more available to residents.

Provide singing and music to enjoy.

Pleasant areas where people with dementia can wander and also enjoy physical exercise.

Having people occupied with something interesting is the key.

Activity suited to their level of confusion or lack of understanding.

After the evening meal the person living with dementia is put into bed by 4.30pm and fed in bed. The person with dementia is in a princess bed normally with music playing, so this is not so much a problem. Others sit at the table then do get to sit and watch TV before being put to bed.

The person with dementia helps people, reads to people and can move from the dementia unit to the general population. This is about lifestyle.

Have a continuous review of programs.

Transition

The transition from home to residential must be smooth. There is a need for support groups for people who are thinking about the move into residential care. Tapping into the right services will eliminate the ‘crisis into hospital’ situation.

The importance of interviewing the aged care facility GP if they are not the same person as the family GP.

Assessment Check Listing

A checklist is good conversation starter to organize specific questions for the individual.

Family carers need to talk to care staff when assessing a facility.

Let facilities know that people coming in to assess them are there to get the best care for people with dementia.

There is better service in smaller aged care facilities rather than larger ones; consumers can get to know the staff in the smaller places.

Questions when choosing care:

- What is the dining room built for?
- Is there professional on the job training?

Food

Food to be appetising and looking good.

Food quality and content choices.

It is small things like the way food is presented, that it is presented as food, that it looks nice, tastes nice for people with dementia and those helping them.

Relationships With Family

Care workers need to be aware of the families’ feelings. They need to respect the dignity and wellbeing of the individual placed in their care. They need to be a conduit for this to happen. Respect for the family means:

- Being open with all communication and making families feel comfortable with asking questions or providing feedback.
- Acknowledging the family are still the primary carer and consulting appropriately.
- Listen: the carer knows your resident better than you do, their likes or dislikes, their medications, activities, behaviours, their social background.
• That the families have a lot of knowledge about the patient and know them the best.
• Learn as much as you can about the person you are caring for from the family.
• Keeping relatives in the loop through residential care meetings.
• Communicate with family members regarding the issues and problems occurring in care.
• Understanding that the family is the advocate for the patient and will be watching out for them. Know that if things are not OK you will hear about it.
• Considering a holistic view of situations in consultation with family.

**Staffing**

Care workers in residential care feel unsupported. There is shifting funding, hours being extended but pay not extended and harder and harder work, including paperwork.

It is sad that care workers, even the highly trained workers, don’t know how to care for people with high care patterns and severe behaviours.

**Staffing Levels**

There needs to be prescribed minimum staffing levels.

Increase pay so more people are encouraged to get into aged care. It is an economic argument.

There needs to be one to one care but it is more like one to twelve to sixteen care.

Availability of placements for students is a problem.

**Staff Training and Education**

*Residential care facilities are ‘where people live’. Carers should be involved in the education process as a ‘humanizing aspect’.*

When the person went into residential care the carer thought the facility had a fair deal of dementia savvy but without real life experience they can be ill equipped physically. There is some training at undergraduate level but the day to day treatment with residents could be a lot better. Add in education with dementia during physio courses and cross that into other professional allied health disciplines.

What training takes place really depends on the mix in aged care facilities, for example home fire training, and CPR training. There should be mandatory dementia training. With big percentage of agency staff there is the need to get them early.

Dementia should be part of the accreditation of nursing homes, including training agency staff. There needs to be a dementia component in the nursing degrees.

Getting care workers trained in dementia care and behaviours towards excellence in nursing homes.

There are barriers to getting the information where facilities are not supporting staff, and money is the priority rather than training staff. There is a need for ongoing sustainable mentoring of staff.

There should be a training audit process for larger organizations across all their facilities.

Recognise and use the passion of GPs who want to collaborate. Training in dementia should be annual and targeted, similar to CPR and food management.

Agency staff are not trained as much because they have to undertake it themselves. Why are aged care facilities using so many agency staff?

Facilities need to have people to show consumers around.

Facilities seeing education as a benefit not a cost: pressuring governments to pressure aged care facilities with education as part of funding and accreditation.

Does education start in training? Need to get education to the managers not just the staff. This is about education being in the system and coming into the system.

Learn the ten rules of Dignity in Care.

Lack of dementia training and knowledge across all categories of staff regarding dementia. If all staff from top to bottom staff had more training in dementia care then other issues such as communication and activity would improve with flow on affects; ie with skills knowledge other issues fall into place.

Need a CD regarding training of professional staff.

Refer to the Alzheimer’s Australia SA Is It Dementia video set.

What about the issue of training people who are not motivated? There needs to be mandated training.

Education of staff to be aware of individual needs.
It is the people that make the difference. If they are task oriented, staff can forget why they are working in a nursing home.

Staff knowledge about hearing aids is limited.

When does staff training occur, in their own time or at work? Is there follow up to make sure the training is effective?

Who is paying for the training?

People should not be working in aged care if they have no training in dementia.

End of Life: Palliative Care

If “your mum has entered the terminal phase of life” how can we make that a good experience?

The term palliative care makes people nervous because of the experiences of people about palliative care.

A survey of GPs indicated numbers who said, “We don’t do dying”.

What is palliative care; what can be accessed?

What is Palliative Care?

There are similarities between dementia and palliative care.

What is palliative care? When there is no curative effect looking after the person’s needs; best care; or on diagnosis make contact with a palliative care team: pain management, comfort care; a holistic approach. At the end of life palliative care is preparing for death, preparing the family.

Palliative care is when you have a terminal illness, giving quality of life / comfort during the journey and caring for the carer.

The Role of Palliative Care

If one has palliative care, there is a better experience of death.

Take palliative care out of the nursing side of things to become care on its own. A carer was traumatized because there was no palliative care for the person with dementia.

Determining what you want to do at the end of life: the role of palliative care.

It is quite difficult to decide when to begin palliative care. It is a focus on quality of life. The person with dementia was not respected in hospital. The carer was there to advocate. If the carer was not there needs would not have been met. The hygiene was poor. The physio said that there was nowhere for people with dementia, even though the person had private cover. At one place the OT did not want to work with the person with dementia.

Along with other documents about end of life care it matters about stating what you want.

Who makes decisions when palliative care comes into play, including guardianship or the person with the Power of Attorney?

Why should people at the end of life be treated by someone they don’t know? GPs don’t have the time.

There are examples of ‘one stop shops’ catering for people living with dementia from diagnosis to the end of life.

Information and Understanding

Australians are hopeless at grief: they don’t like it if you cry. Even other members of the family didn’t understand what the carer did and went through.
Develop palliative care packages for consumers, for example, for those living with memory loss when it is appropriate. A fact sheet on palliative care would validate people living with dementia asking for palliative care.

Level of activity in teenage-hood: very early education.

Understanding of palliative with people with dementia.

There is stigma attached to palliative care.

People don’t talk about dementia or palliative care: “this won’t happen to me”

Positive press included the media increasingly talking about advance care directives.

Grief and Loss

There were gaps in understanding the grief and loss during the time of supporting the person with dementia and the level of support. People don’t understand the grief the carers and family feel. This is not anticipatory less than an ambiguous grief. It is like the person has died twice.

Diversity

Grief is hidden in CALD communities. People get to a crisis because there is no support from other people. There are shame barriers because of taboos. The Chinese community is collaborating with Flinders University on research for people over 50 with dementia.

Quality of Life

It seemed that no-one cared for the person’s quality of life. They did not understand the ambiguity of the grief nor the impact of the grief.

We could not find anyone to undertake rehabilitation. When the person with dementia tips into the point of no talk or walk they go into a wheelchair. You have to make the best of it to get them into the sun, into the garden.

Depression by people with dementia at end of life stages highlights the negative aspects. We need more concentration on living well with dementia.

When referring someone with dementia in a hospital, program staff need to think about the whole person, about their needs and about who they were.

After the hospital stay they were honoring the person with dementia as a person, but people think the things you do are peculiar.

Planning For End of Life

Setting things in place while people have capacity.

Don’t leave it until the last minute to tell family. Aged care facilities and others do not know what to do. You need time to work everything out, to get things off the ground.

Being realistic about what is the best place for someone at end of life.

You need to plan for palliative care.

Flexibility

Living and dying ‘in place’.

In 2010 we were told the person with dementia would probably die after a fall. The GP said “I’m guided by you.” Palliative care needs flexible treatment, not non care.

The Role of Family

Long relationships, such as being married for 58 years makes a big difference to how to approach the situation.

At Aged Care Facilities

In residential care the last 24-48 hours were particularly poor. The family was really involved over the last two to three weeks but not one person asked the carer how she thought her mother was feeling or how the carer was doing.

In residential settings there are lots of procedures for staff to follow but it is the ‘little things’ that make a difference.

One third of nursing home care is palliative care mainly for pain relief. Palliative is people oriented, for example, letting people know it is fine to hold their hand.

Residential care facilities are doing quite a lot with palliative care at various levels.

Much up-skilling of aged care facility staff. Different facilities have different practices.

Communication with facilities is important.
OTHER

I am a better individual because of the journey I am on. People should concentrate on the positives, share the positives.

There is an inevitability of dementia terminology needing a different set of rules, for example, community understanding of dementia as palliative.

People with dementia know if you are ‘present’, giving them your full attention.

Australia has never worked out how to care for old people.

Make a difference through perseverance. We need to keep ‘screaming’ at politicians.

A re-setting of the ‘norm’.

There has been some progress in dementia care becoming one of 10 accreditation points in hospitals.

See the dementia journey as whole continuum, not as a series of barriers.

Develop a mix of education and understanding resources between individual workers in aged care facilities.

List dementia friendly businesses on the Alzheimer’s Australia SA webpage.

More research into fronto-temporal dementia meaning more money needs to be available. Putting things in place – dementia impact is huge reducing choices.

‘The System’

Making changes in the system is so difficult.

Sharing good ideas with other organisations.

Finances

Centrelink; why does a person diagnosed with Alzheimer’s have to be assessed for ‘work capacity’?

Having advice regarding accessing superannuation early; finances for residential care.

Unable to handle money; worried about losing a volunteer role.

We are concerned about future financial help.

We need access to disability payment.

Younger Onset Dementia

Support is needed for those who want to stay in the workforce, in particular training to employers.

“Retirement at 50”? With younger onset dementia?

The Future

The unknown future.

What is ahead and how can I prepare for it?