Rural Tasmanian dementia health care model

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DEMOGRAPHY

The Tasmanian population is the most dispersed in Australia and as everywhere there is a major increase in older people with great social change and break up of family, assurance of a family carer is doubtful. The need for community support will increase. Of all the pathologies that come with aging, the ones of epidemic proportions are dementia and osteoporosis. Education can prevent osteoporosis but not dementia. Increased research funding into its origin and prevention is required. Forward planning is essential for the sufferer and carer.

AETIOLOGY

Alzheimer’s, one of the dementias, is an organic psychosis where there is structural or chemical damage to the brain. It is chronic, insidious in onset, long in its course and usually incurable.

This paper is confined to Alzheimer’s and Vascular Dementia both unlike physical diseases where in early signs and symptoms are mostly identical.

No two people are alike making diagnosis difficult especially before a post mortem examination. Accurate estimates of the percentage of people with dementia are indefinite but likely to be between 55 and 65% of the population. Vascular dementia caused by ministrokes showing similar variable symptoms as Alzheimer’s is more common in men than women.

Dementia is not an abstract entity but an illness that will touch most of us directly or indirectly.

A dementia sufferer starts a journey into the unknown. Changes include emotional bewilderment, fear of the unknown, knowing something is happening but not knowing what or how to deal with the strange new frustrations. There are degrees of change in personality for the sufferer that are bewildering and frightening for the carer and family.

A person’s emotional, social and psychological needs do not disappear with the onset. A more positive attitude is needed with the sufferer and those working with the family to help them understand what is happening.

It absolutely devastated me when my husband of 50 years developed dementia. He looked the same but it was like there was a stranger inside. I wasn’t able to say goodbye properly to him. Worst of all a lot of our friends stopped coming by.
COMMUNITY AWARENESS

Carers of people suffering dementia in rural and remote areas need specific and flexible strategies to assist them. There are important differences between urban and rural people. Country people like privacy, are very scared of the stigma still associated with dementia and how it affects them in the community. Because services are not so plentiful they are often more resourceful, think more laterally and tend to be self-reliant. In the case of dementia—as a family they will try to cope alone for longer—sometimes leaving it too late to find a specific way to help the sufferer. They will always improvise until they can no longer cope. In town services are readily available. A little help in understanding dementia allows a usually concerned community to support rather than isolate one of their own.

My husband was a big strong man in his 60s when he got dementia. We lived in a small farming community and I wanted to keep him at home for as long as possible. But he used to run away—up the country roads and across the paddocks in his pyjamas. I knew the neighbours used to laugh and say we had had an argument so I decided to do something about it. I organised a knife and fork tea at the church and invited as many people as I could. I invited the carer support worker and she talked about dementia. Next time my husband ran away the nearby farmer brought him back and gave me a hand around the yard. Knowing what it was about made a huge difference.

Cape Barron Island; a very small, largely aboriginal population had never been confronted with dementia. People were very frightened by the behaviour of a demented woman, which alienated her from the community. Helping them understand dementia and how to deal with it resulted in the lady being back as a functioning member of the community within 6 months. People were almost on a roster operating as a family unit helping with menial tasks.

UNIQUE SUPPORT SERVICE—WESTBURY

A unique rural support service for clients and carers of people with Alzheimer’s is at Westbury Community Centre. It is an on the ground practical service based in a very rural region demonstrating a fundamental way of addressing needs. It highlights in microcosm the major factors basic to good practice in interlinking available urban services within regional ones.

The Rural Westbury Centre aims:

- to enable the person with Alzheimer’s to remain at home as long as possible
- to help the carer cope with daily living, with strategies to deal with the sufferer and in the transition from home to appropriate residential care
- to select and train appropriate staff
- to raise community awareness of all who may come in contact with the sufferer e.g. banks, taxi drivers, shops, cleaners etc
- to show the value of a special rural dementia unit in a community centre.
Two buses take people to and from the centre. A HAAC bus operates from Launceston travelling the main road—the Centre community bus services outlying areas. A car is also available.

The Westbury Centre is a well-appointed, multi-disciplinary unit with adequate parking where a special dementia area is set-aside.

Work at the Centre is a form of rehabilitation addressing the challenge of dementia. Each Alzheimer sufferer is unique so finding a new role for the new identity and changed personality of the client is necessary. With cognitive failures, sufferers can only cope with a simple task or one thought at a time. Activities that do not lead to failure, stimulate and give confidence in “doing” are important. It is a case of dementia survival with dignity. The co-ordinator of the service does not act entirely alone but can link in with support services, some local, some urban. Respite for the sufferer and carer is vital. Westbury recognises this and values it being offered locally.

Of particular note is the specialised assistance offered by the Launceston Dementia Care team— their ability to empathise, understand, support and manage client behavioural difficulties is of inestimable value to the rural centre.

**THE CENTRE**

The special dementia section of the Westbury Community Health Centre has created a warm, friendly environment for the Monday and Friday Club. An uncluttered, quiet sunny room with a rural outlook is appropriately furnished with comfortable lounge chairs, dining chairs and table. There are not too many people as clients rarely fit into, or cope with, the usual noisy, busy, much larger day centres which causes over stimulation, agitation and lost feelings. This often leads to wandering or unacceptable behaviour. The décor is quiet and homely. There is a bathroom so clients can be helped to bath. This is often quite impossible at home.

Early morning sun stays most of the day. A door leads to a secure garden area where clients can wander freely without danger or obvious restriction and can enjoy activities.

Clients can see sheep and horses grazing and each day become quite excited at the sight of a train. In Tasmania this is a rare sight. Clients on arrival join with members of the other day centre for morning tea but they soon feel restless and seek their own non-threatening clubroom.

The day begins with exercises followed by a game involving motor skills. Lunch is served by volunteers. Soft “old time” music forms a background and often challenges the memory. After lunch a walk to see the day old lambs or steamrollers and ploughing equipment pulled by a bullock. Westbury is lucky to still have these things.

Back to the clubhouse, afternoon tea and reminiscing. Morning and afternoon tea are very important because appetite and pleasure from food continues unabated until the end stage or physical ailments supervene.
Other activities include massage, reading and discussion of the local newspaper, video, quoits, schouten board, snakes and ladders, music games, sing along etc all thoroughly enjoyed.

Throughout the day the client needs much reassurance, that they are safe, that they will be cared for, that you know where they live and you will be taking them home, or that their loved one has the centre’s phone number if the family needs them. It is important to follow this through so the client remains free of anxiety.

The day club is never more than 7 members so that with a smaller number they feel safe. They meet twice a week, Mondays and Fridays. Community transport is available with the co-ordinator from 9.00 am to 3.00 pm for the total cost of $7.00.

The day centre has a salaried staff of one co-ordinator/facilitator who has worked with the Alzheimer’s Association for 7 years, supported by two carefully chosen volunteers committed to continuity attendance. The co-ordinator provides a sensitive understanding of dementia and ongoing education.

**REACTIONS TO OVERSTIMULATION**

It is probable that some people with dementia live in a state of almost constant fear. They cannot understand what is happening, or think clearly, every new face, or even and old one could be a threat.

Without meaningful activities it is quite probable that some people's lives can be very empty. They may attempt to fill this emptiness with wandering, repetitive questioning and many other attention seeking behaviours. There is a fine line between meaningful activity and overstressing. Careful evaluation of each person is essential. Activities that confirm their dignity give pleasure and ensure success. Failure reinforces feelings of inadequacy and adds to anxiety. It is important to provide tasks that are simple and unhurried and stopped immediately if the client becomes tired, irritable or restless. Each client is closely monitored for obvious change in behaviour. It is important to act at once in order to define the possible adverse behavioural reaction.

A client, paranoid, who hallucinated and was a wanderer, was really worried about a herd of elephants walking through her home as well as at the centre.

We tried to herd them out the door but they came back. We shot them however more came back. She was so tortured by the elephants we had to think laterally and decided to put a computer printed sign on a fly spray can that read ELEPHANT REPELLENT. Each time the elephants came through the door we sprayed them with the repellent and she was always happy as it got rid of them.

**TRAUMA REVISTIED**

Trauma, which is part of life experience, can be harder for people to struggle with as they age. Whatever the trauma; the loss of a child, a loved one, the experience of war, accident, homicide, violence or sexual abuse, issues that are unresolved life events can often cause distress in old age.

Someone walking with a heavy tread in a passageway caused one client to go quite berserk. He had been a POW and he remembered that sound which heralded torture.
Research shows enormous benefits through therapeutic intervention. Tasmania has no trained specialist community workers in validation therapy. In recent years two specialist areas of aged care and trauma counselling have ongoing liaison and communication and a partnership has been established between the Community Dementia Team, Community Health Divisional Therapy and Social Work and the Northern Sexual Assault Trauma Support Service. This fills an existing service gap.

ACCESS TO THE CENTRE

Clients diagnosed with dementia can be referred by family members, GPs, community nurses and other professionals.

When referrals are made the co-ordinator meets the carer and the sufferer before introduction to the centre. If there is a problem enticing the client to leave the security of home (and there often is) it is vital that a befriending program is implemented to build a trusting relationship and gently encourage the person to leave his/her safety net. This may take time.

Staff need the ability to give quiet reassurance to the carer who is often as bewildered as the client and needs a great deal of support in their new and very difficult role. Unpredictable behaviours and aggression causes the carer stress and guilt. A familiar mode of interaction between husband and wife is no longer possible—a fact that is extremely difficult to accept.

It takes time to build confidence in the co-ordinator and staff of the centre and it is essential that all in contact with the sufferer work as a team. A bad experience for the client can mean the end to any real support which could be devastating to both the carer and sufferer.

A wife had taken many weeks nurturing to accept that her husband would be ok in respite allowing her two weeks of peace at home without too much guilt. She had not been able to take him to respite herself because of his agitation and behaviour and the blame she would experience. It was agreed that nothing would be said to him in advance. After much reassurance the wife left thing to the co-ordinator. She packed her husband’s bag and left it outside her front door for me to put in the car boot. The husband was used to me after several befriending sessions. When I arrived he was showering, attended by a support worker. There was a terrible outburst in the bathroom when we she told him he was going away today and would have a good holiday. He was panicked and very aggressive towards his wife—she had betrayed him and he was not going anywhere. We had lost all we had worked so hard for and his wife was too afraid to accept residential care again. If it is a bad experience the first time you have usually lost the future unless an enormous amount of groundwork is done again, not only with the person but with the primary carer as well. All handling a sufferer need dementia training and need to work as a team.

A comprehensive social history of the client enables activities suitable to the known life style to be introduced. Knowing the likes and dislikes of the person can minimise triggers to adverse behaviour. Filling in a small diary about the day’s activities, keeps the carer informed about the day’s events with. Ongoing communication with the family highlights problems which may arise, whether at home or in day respite and through discussion these conditions can be minimised.
ASSESSMENT

Assessment is carried out by the co-ordinator to see the person meets the required criteria e.g. is mobile and is continent. If a client shows aggression to a staff member or other client every effort will be made to find the trigger and attempt to modify it with a positive outcome. The management of difficult behaviour depends largely on the insight and skill of the staff and to a small part on medical intervention. If the behaviour persists discussion with the client’s GP and family members to review the situation and decide on an appropriate solution.

A major problem with assessment lies in lack of co-ordination of those assessing the needs of dementia sufferers. Good care management is needed to co-ordinate the services to avoid duplication.

Carers

Carers needs are great and consume a large part of the co-ordinators time.

It is estimated that 75% of people with dementia live in the community. Families and voluntary carers enable this and provide the necessary informal care. They reduce the pressure in residential aged care facilities representing a major saving to funding bodies.

Carers need great understanding and support. This is often overlooked. Carers are often the persons providing most of the personal needs and usually have little or no helpful training. Their distress caused by uncertainty can add to the he sufferer’s fear. The carer needs education, personal and otherwise care for their back and joints, to understand showering, bathing, dressing the sufferer etc. to manage incontinence, available aids, meal times and the confusion the sufferer may have with feeding themselves. Practical demonstrations can build their confidence whilst they struggle to manage.

Practical interaction with the centre facilitator provides care where previously they would have given up.

A day club client, Norah, is cared for solely by her husband William. He worked professionally for many years with dementia sufferers but is now isolated whilst providing 24-hour care for his wife. He finds home care extremely challenging and very different from work. Initially William would tell Norah every morning of that day’s activities. Norah would be quite agitated by the time we arrived causing William to stress and feel guilty. Once Norah was on the bus and William was no longer in sight she would settle down and enjoy the day. We had to persuade William not to tell Norah of the day ahead. He took heed, left it to us to tell her where we were going and before she became agitated or upset we had her in the bus. We decided to video Norah participating in activities to reassure William. Norah’s agitation prevents bathing at home. She now has a bath at the centre with the same two caring girls bathing her each week. Initially she became distraught but has now settled. The centre bathroom is softly decorated and heated, soft music is played and the client is encouraged to have a nice relaxing bath taking as much time as they like. The community nurse and Family Based Care work closely with Norah. Much liaison is done through these agencies to help William in his difficult caring role as Norah’s dementia progresses.

The carer may have significant difficulties coping with daily tasks formerly handled by the sufferer e.g. handling money, driving, household duties, recognising family or
friends etc. It means the old way of life has altered; sharing ceased and caring has become a 24-hour task. Their needs are in the home as well as respite.

As deterioration occurs new ways of coping are needed. When meaningful speech reduces it becomes even harder to understand and manage a person. It is difficult for the family to accept placement of the sufferer in a secure centre. Feelings of guilt, ambivalence about the timing, helplessness, frustration, sadness etc, take an emotional toll which can physically affect their health and make coping very difficult. These feelings can last with the carer some years even after the death of their loved one unless they are assisted in learning how to move on.

**General practitioners**

Working closely with the nearest doctor is a big advantage especially when medication is required and needs monitoring. However GPs are in a difficult position. They are expected to provide early diagnosis of dementia—often a very difficult task. Some GPs have a particular interest in older patients but many do not have the time or training to give the personal support needed. Sometimes the GP may overlook the vital role of the carer. In the early stages, possibly because of fear, the patient is remarkably good at camouflaging making diagnosing very difficult.

My husband was always asleep in his chair when our sons visited. They thought he must have been sick. We realised later that he knew he could not remember things and he was hiding this from the boys by pretending to be asleep.

Through the University of NSW Professors Henry Brodarty and Dimity Pond have been funded to develop a rapid dementia assessment tool suitable for use in general practice.

**Community nurses**

Community nurses can play a vital role in recognising early behaviour deterioration. Some are particularly interested in and excellent with dementia sufferers. They are particularly valuable for people who live alone without family support. Such nurses need further specific understanding of dementia. To date, insufficient education has been available.

**Community**

An educational program to raise awareness makes a tremendous difference in small communities. Understanding can remove the stigma and help the sufferer and carer.

Mrs X has dementia but still lives at home in a little country town. The support of the community lets her continue to live her life where she wants to be. The understanding of the hairdressing salon which she visits nearly every day, backcomb and spray her hair, yet she believes she has had the full treatment. When she wants to pay the hairdresser they usually say she paid extra last week. The corner store and butcher also watch out for her and they know if she is buying food, is up and about. When she is not they let people know.
RECOMMENDATIONS

1. That service providers be encouraged to develop dementia specific day centres with secure areas in rural community centres.

2. That a common assessment tool and case management model be developed to avoid over assessment and improve service co-ordination.

3. That the role of carers be acknowledged and there be recognition that carers require emotional and financial support, education, training, domiciliary and respite services.

4. That a broad ongoing education campaign be undertaken to raise public awareness of dementia, increase understanding for workers and help to remove the stigma.

PRACTICAL CHANGES TO SERVICE DELIVERY

1. More dementia specific rural health centres.

2. More selected and trained dementia co-ordinators, staff and volunteers.

3. Community education

4. Essential funding.

Rather than build a wall to keep out the wind (of change) we must build a windmill to generate the tremendous power that education and continual learning can bring.

Let us hope the winds of change are gradually gaining the momentum needed to alleviate the distress caused by Alzheimer’s Disease and Vascular Dementia. At the moment a hurricane is needed!

POLICY

That the division of Community Rural Health support the development of national guidelines, standards and accreditation for dementia specific training for service providers.
PRESENTER

Mollie Campbell-Smith of Launceston, Tasmania is a Bachelor of Science graduate of the Melbourne University and holds a Tasmanian University Diploma of Education. She also is a life member of the Australian College of Education.

For over 30 years Mollie was a senior biology teacher, school counsellor and interpersonal relations and communications teacher in many Launceston schools.

Mollie’s voluntary positions include:

- Member State Dementia Care Plan Team
- Past board member Alzheimer’s Association Launceston and Regional Committee member
- Chairman Older Person’s Reference Group (an association of organisations encouraging positive ageing)
- Member Tasmanian Positive Ageing Consultative Committee
- Past Vice President National Council of Women of Australia
- Past President of Tasmanian and Australian National Council of Women
- Adviser for health working in conjunction with the adviser for ageing for the National Council of Women
- Vice President Richmond Fellowship Tasmania.
- Tutor – Lifelink telephone counselling service.

Most recently Mollie has been invited to join the Aged Care Planning Advisory Committee for the Commonwealth Department of Health and Ageing.
APPENDIX 1—EDUCATION AND TRAINING IN TASMANIA

Information and education are fundamental in changing attitudes toward dementia. There is still fear by many people.

One wife said, “A lot of our friends stopped visiting—I don’t think they knew what to do or say. I remember one having to leave almost as soon as he got there and I found him crying outside because he couldn’t cope with the drastic change in my husband”.

A broad ongoing education campaign is needed to raise public awareness, increase understanding and remove the stigma.

However specific education is vastly different to raising community awareness of the disease. People who have an innate ability to relate to the difficulties of dementia sufferers find supportive education tailored to their needs essential and of inestimable value.

In Tasmania dementia education occurs in an ad hoc manner across the State. There is no structure, standard or consistency in training courses and some occur as a result of once off funding to community groups.

It is important for the Division of Community and Rural Health to support the implementation of National training guidelines, standards and accreditation to ensure consistency in dementia specific training for service providers.

In 2001 in Hobart, Tasmania, a National Staff Development and Training Award for Residential Aged Care facilities was won by “Adards” Nursing Home. “Adards” continually conducts dementia specific training for everyone from the receptionist, cook and cleaner to be Registered Nurses. These courses are in great demand.

The present information technology explosion offers great possibilities especially for rural areas. The trial “On Line Dementia Education” program report shows great potential and has identified a number of areas that will need attention. Before the trial analysis identified gaps and opportunities for a new program to support rural and remote health workers, professionals, clients and carers.

An interactive and support program on dementia was conducted using video conferencing facilities. This was innovative, met needs, raised others and an evaluation showed huge potential. There are wide raging possibilities eg reaching Flinders and King Islands and remote areas of the East and West Coasts. It is cost effective, reduces travel time, time lost from other duties, stress etc.

The program identified the following major needs:

- clinical support and education
- management of client support and general information
- education on legal and responsibility issues
- training courses eg validation therapy and Personal Carer Competencies.
A number of new educational initiatives have been instigated:

- new bridging program by the Psycho geriatric Unit to assist people with dementia at home whilst waiting placement
- the development of a comprehensive dementia training program workshop
- five-day dementia training session at Meercroft Home (Devonport) for all workers and professionals by a skilled professional – Mary Davies
- dementia specific training for Family Based employees in the North and North West by Anne Kelly, a nationally accredited educator
- the Tasmanian School of Nursing now offers clinical placements for undergraduate students in aged care facilities
- initiatives instigated by the nursing fraternity in Circular Head has resulted in a survey of dementia carers and their concerns by the University of Tasmania Division of General Practitioners
- the Dementia and Alzheimer’s Association plan to put a mobile van on the road covering 15 sites throughout Tasmania to establish a broad awareness program set up a volunteer network and provide a program for family carers. It will work from on line centres in the towns visited. The Association will provide a virtual support group and virtual help line.

The future is not all doom and gloom but awareness is essential. People with dementia, their families and carers are vulnerable, have increasing dependency and need much personal help and reassurance. Selection and personal training of those working directly with the client or carer are the key components.

Another area where education is needed is in the re-evaluation of residential care nursing homes, many are not specifically designed for dementia and neither the environment or care provided has moved on from traditional practice.

The environment and nursing needs to be specific, present aged care facilities are not. Future needs must be addressed and planned for now.

“Adards” is a good example of a dementia specific residence. The development of services to support people at home means the development of care packages, highly individual and delivered by dementia experts in conjunction with the family.

The nation has not yet grasped the impact of population aging, great cultural change, change in government systems, building design engineering etc. All need forward planning.
APPENDIX 2—DEMENTIA CARE PLAN FOR TASMANIA

In 1999 a Dementia Care Plan for Tasmania was produced. Its basis was a series of community forums held at strategic places to cover the Island to gain a profile of the perceived existing needs. A Dementia Care Plan steering committee, a clinical and a community service group, worked for nearly two and a half years to address the 21 recommendations of the Tasmania Care Plan.

To date the production of a Dementia Services Directions Discussion paper shows:

- service components and a recommended pathway for care
- a data base of current education courses
- a telehealth dementia education series for rural and remote health workers
- a start for dementia HAAC packages of care
- the beginning of a psycho geriatric service to the NW and adjacent islands, King and Flinders under the Medical Specialist Outreach Assistance program
- all specialist services are now placed within Mental Health Services.

Some recommendations require ongoing work. Much more needs to be done especially on access to services, education and the provision of additional support for clients, carers and service providers.
APPENDIX 3—WHERE TO FROM HERE?

Services needed in the community

- GP who is interested and works with the centre
- Key workers/staff selection and training
- Carer education training
- Carer support groups accessible to all carers
- Community and professional education
- Domiciliary support:
  - nursing
  - personal care
  - domestic and handyman service
  - incontinent laundry
- Respite:
  - day care dementia specific
  - in home respite
  - weekend and holiday
- Funding staff and transport interlinking of services
- Services needed by carers:
  - GP
  - dementia specific key workers
  - support for whole course of disease
  - key worker advice counselling
  - key worker assistance with services
  - carer support groups
  - carer education
  - domiciliary help
  - respite