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A publication of
Alzheimer's Queensland.

Dementia Matters

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Alzheimer's Queensland

Alzheimer's Queensland is Queensland's largest not-for-profit community organisation whose primary aim is to maintain the quality of life of people with dementia and their caregivers. We support the desire of most people to remain living in their own home as long as possible and assist families and caregivers to facilitate this.

We aim to do this by offering the following:

Statewide Information, Education and Support Services:

- 24 hour 7 days per week professionally staffed Dementia Helpline (ph: 1800 639 331)
- Community education
- Library resources
- Interactive website at www.alzheimersonline.org
- Professional education
- Family carer education
- Support groups – face to face and telephone support groups
- Individualised support
- Fact sheets and specific information requests posted as required
- Dementia Matters newsletter

Alzheimer's Queensland

47 Tryon Street
Upper Mt Gravatt Qld 4122
Telephone: (07) 3422 3000
Fax: (07) 3343 2557
Email: helpline@alzheimersonline.org
Website: www.alzheimersonline.org
Dementia Helpline: 1800 639 331

Dementia Design ATSA Expo

The Alzheimer's Queensland Design Team successfully brought Dementia Design for the first time ever to the 2015 ATSA Independent Living Expo Brisbane.

Our team hosted a 2-hour workshop 'Design for Life' on May 6th that was well received. This session laid out the key dementia design principles and how these can be adopted on varying scales to create comfortable, enriching spaces both in one's home and in an aged care facility.

Alzheimer's Queensland also set-up display rooms based on dementia design principles for viewing by exhibition attendees on May 7th. The displays were a perfect example of how a considered selection of health care equipment and design of environmental features promote homeliness, supportive care and functional independence for people with dementia.

For education and consultation services on dementia design contact the Alzheimer's Queensland Design Team on 1800 639 331 or email: bdm@alzqld.org.au.

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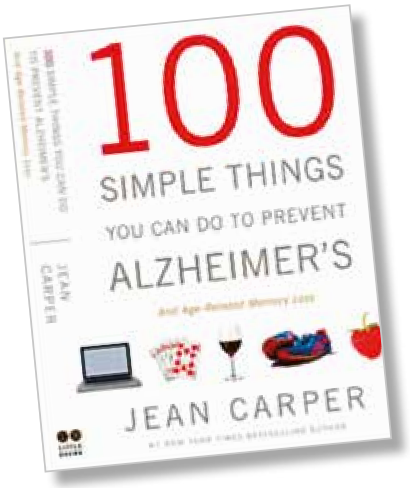
100 Simple things you can do to prevent alzheimer's and age-related memory loss

Author Jean Carper

A new reading addition to the Alzheimers Queensland library. Jean stated "On many levels, Alzheimer's research is an exciting grab bag of uncertain theories, despite a hard core centre of scientific belief. Certainty about cause and preventative interventions has not yet been engraved in stone. So while this book includes preventative measures based on research by credentialed investigators, the information and advice contained in this book should not be interpreted as a definitive way to prevent Alzheimers but rather as a guide to suggested measures that may help prevent Alzheimer's.

Jean dedicates a chapter to each of the 100 recommendations including monitoring blood pressure, eat berries every day, keep active, be an extrovert, keep infections away, keep insulin normal, practive meditation, get help for sleep apnea, cut down on sugar, take care of your teeth, follow a Mediterranean diet, get enough Vitamin b12 and D and the list goes on...



Early diagnosis of Alzheimer's Disease: Biomarkers and Brain Imaging

The diagnosis of Alzheimer's disease currently relies largely on documenting decline in memory, cognition and function over time. Sadly, it is known that Alzheimer's disease will already have caused significant and irreversible damage to the brain when it is diagnosed after behavioural and cognitive symptoms have already appeared. While physical examination, blood tests and brain scans allow doctors to exclude other possible causes of the presenting symptoms, for the most part these tests do not currently assist doctors to make a specific and early diagnosis of Alzheimer's disease.

New research advances are very encouraging that in the future, rather than facing a long wait to see if symptoms get worse before a diagnosis of Alzheimer's disease is made, a blood test, spinal fluid test or a brain scan will allow diagnosis earlier in the course of the disease before symptoms even present.

Scientists are now looking at the use of biomarkers (short for biological markers) and advanced brain imaging techniques to diagnose Alzheimer's disease and other forms of dementia in the very early stages before cognitive and behavioural symptoms occur.

A biomarker is any substance occurring in the body that can be measured to indicate the presence of a particular disease. For example, blood sugar levels are a biomarker that is measured to indicate the presence of diabetes. Biomarkers can be used for diagnosis, to measure how a disease is progressing and to assess the effectiveness of treatments used.

Biomarkers for diagnosis of Alzheimer's disease are currently being researched to find a simple, inexpensive and accurate way to diagnose Alzheimer's disease and other forms of dementia before the onset of symptoms. If this can be achieved, future treatments can then be targeted to the disease at its very earliest stages before symptoms develop and irreversible brain damage and mental decline have occurred.

Cerebrospinal Fluid Biomarkers

Cerebrospinal fluid (CSF) is a clear fluid which surrounds and cushions the brain and spinal cord. Currently, the most accepted and advanced method of diagnosing probable Alzheimer's disease is through measuring CSF levels of two proteins, beta-amyloid and tau. Amyloid is the protein which forms plaques in the brains of people with Alzheimer's disease and tau is the protein which forms neurofibrillary tangles. Research indicates that these two proteins show changes in their levels in the spinal fluid of people with Alzheimer's disease with amyloid levels being reduced and levels of tau increasing. The drawback of measuring biomarkers in CSF is that it requires a lumbar puncture, an invasive procedure with potential side effects. This makes screening and follow-up over time difficult. Clinical trials of new drugs for Alzheimer's disease are now incorporating measurement of amyloid and tau in CSF as a tool for measuring the effectiveness of these drugs in preventing plaque and tangle development in the brain.

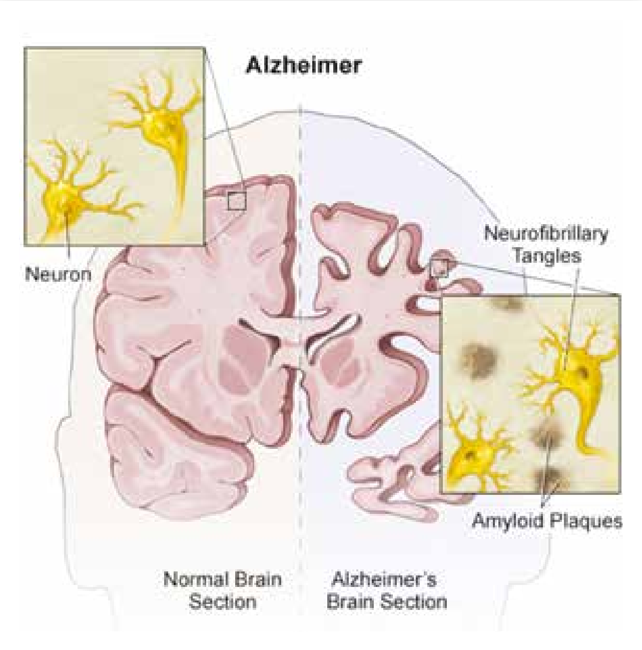


Image credit: University of Chicago Medicine

Blood Biomarkers

A great deal of research is currently focussing on the development of a blood test for accurate and early diagnosis of Alzheimer's disease and a number of biomarkers, including amyloid and tau, are being investigated. One area of research has demonstrated that there are differences in some proteins (complement factor H and alpha-2-macroglobulin) in the blood of people not only with Alzheimer's disease but those with pre-Alzheimer's states such as mild cognitive impairment. This is exciting news because it indicates that these proteins may possibly act as very early markers of Alzheimer's disease.

The development of a blood test for Alzheimer's disease would be a significant advance in diagnosis as a blood test for these biomarkers would mean a simple, fast, inexpensive and widely available diagnostic tool for doctors. However, currently the biomarker types and concentrations in blood which accurately indicate the presence of Alzheimer's disease requires further investigation.

Other biomarkers

Urine, saliva and eye secretions biomarkers are also currently being researched. One recent area of research is investigating whether early Alzheimer's disease is detectable through characteristic deposits of beta-amyloid in the lens of the eye. While these tests would be quick, inexpensive and non-invasive, more research is needed to understand the correlation of these biomarkers with Alzheimer's disease pathologies and to develop sensitive tests to detect the low levels of the biomarkers in these body fluids.

Further biomarkers will be discussed in the next issues. References on request.

Dementia: How did we get it so wrong?

Article by Dr Jane Tolman, Associate Professor of aged care
Director of aged care, Royal Hobart Hospital

I recently had the privilege of participating in the second running of the Massive Open Online Course (MOOC) on Understanding Dementia run by the Wicking Dementia Research and Education Centre at the University of Tasmania. This has provided a forum for learning and discussion about dementia for fifteen thousand carers, health professionals and interested persons from around the world. More than that, the participants are able to seek answers to their questions, and to tell us their concerns about their "journey" and about their expectations.

I think there is much room for improvement in the way health professionals have dealt with dementia.

We handle the diagnosis of dementia very badly. Families complain that doctors are unwilling to make the diagnosis, defer the diagnosis, or deny the diagnosis (just getting old). Statistics tell us that only about forty percent of people with dementia ever get a diagnosis. There are established sets of criteria for diagnosis; but many of us still use a cut-off score, on a basic cognitive test to make a diagnosis, maintain that a diagnosis can only be made post – mortem with a biopsy, or tell our patients that it is a diagnosis "of exclusion". While evidence suggests that the personal story ("history in doctors' language) offers considerably more weight to a diagnosis that any examination finding a test, families still find it hard to put their case, present their information and are sometime dismissed due to privacy issues.

Notoriously, people with dementia develop a lack of understanding of their situation. Doctors call this "lack of insight". People with dementia also lack skills required to make good decisions, to reason and to solve problems. These features of dementia are poorly recognised by many health professionals. And yet they can expose the person with dementia to extreme danger. Assessing cognitive capacity for decision-making can be challenging. Many clinicians are hesitant about providing an assessment, and many who do so, provide an inadequate assessment. It is essential that doctors embrace this role, and develop their competence in such assessments.

What families most want to know about dementia is what will happen as the condition progresses. When we do make a diagnosis, we rarely address this. Current staging systems of dementia tend to focus on what people can do rather than what their needs are, are often designed for research, and rarely address the real need: how to provide dignity to very vulnerable people. At the time of diagnosis, or soon after, loved ones (and the person with dementia where relevant) should be given information about the stages ahead and what they mean. There should be a "road map" to help people navigate the path.

Dementia is often described as a memory problem and clinics for its diagnosis and management are still sometimes labelled as Memory Clinics. It's time that we acknowledge that dementia is about a range of domains, including:

Cognitive – memory, language, insight, judgement, planning, reasoning;

Function – inability to perform household and other tasks and ultimately person care;

Psychiatric – commonly delusions, hallucinations and depression;

Behavioural – aggression, screaming, following, calling out; and

Physical – swallowing, continence, mobility and eating.

Families and carers have the right to know the facts. When these symptoms of dementia arise, families should not be surprised and need to be able to recognise these as manifestations of the disease.

Dementia is a relentlessly progressive terminal illness. As a profession we have failed to identify dementia as a disease which has much more in common with cancer than with forgetfulness. At the time of diagnosis of other neurodegenerative conditions such as Motor Neuron Disease, a palliative approach is often instituted from the start, and early decisions are made about future feeding and assisted breathing. But in case of dementia, we often offer families few choices, because we have failed to recognise that quality of life will be compromised, or to identify the role quality of life plays in decisions about management.

The behaviour and psychological symptoms of dementia are common, and yet they are poorly understood by many of us. Many clinicians offer treatments which have little (or sometimes no) demonstrated usefulness and which have well documented adverse effects. We continue to offer medications which sometimes only work by virtue of their sedating effects, and we fail to communicate the facts to families. The best evidence from international data is that at best twenty percent of those with dementia who receive antipsychotic medication for the treatment of behavioural and psychological symptoms derive benefit. Despite this evidence, up to eighty percent of residents of aged care facilities who have dementia are regularly taking antipsychotic medication.

Despite the rhetoric, we rarely practise holistic, person-centred medicine when it comes to dementia. This would mean the following: acknowledging that every person with dementia is a unique case; providing the knowledge which is essential in making wise decisions about management, and being aware of the evidence; ensuring that there is a decision maker who can make informed decisions (in collaboration with the clinician); offering choices, and perhaps above all ensuring that this, of all conditions, requires a very clear focus on dignity for the person with dementia , and careful consideration of the best way of providing it. Management of dementia should always be collaboration between the person with dementia, their loved ones, the medical team and paid carers.

The MOOC has taught me that we need to listen more to those who live with dementia; that is, to the carers, loved ones and professionals. We can provide good care for those with dementia but in many ways we need to go back to the basics. We also need to make sure that we listen to carers, engage them in management and acknowledge the critical role of education.

Benefits of Gordon park respite centre

The symptoms of dementia can impact every aspect of an individual's life. Progressive deterioration in thinking processes, like memory, concentration, initiation, problem solving and reasoning often prevent someone from engaging and participating in life independently and the end result is a reduced quality of life. Community respite provides the opportunity for social contact and participation in activities within the community. A more active connection with the environment will improve mood, energy levels, reduce levels of anxiety, help maintain physical and cognitive functions and also language. The old saying, 'If we don't use it, we'll loose it!' rings true.

Personal enjoyment is improved by a sense of belonging through actively participating in daily life activities. Dementia more often than not impacts on an individual's capacity to self initiate engagement in activities and assistance is needed. Past activity planning in both residential and respite facilities have often infantilised people with dementia, through unsuitable activities and activity planning.

Pic. Of Ron and Joy*

At Gordon Park Respite Centre we design activities that are meaningful and purposeful for clients, and are able to help people actively engage in the activities rather than be passive bystanders in their own worlds.

Regular weekly activities at Gordon Park Respite Centre such as, reading stories to kindergarden children, participating in Meals on Wheels, hydrotherapy, audio book club and woodturning, allow individuals to pursue and actively participate in their interests with a little help from staff. The activities are designed according to their personal interests and functional levels, rather than a one size fits all approach. Staff are trained to assist only where needed to provide just the right amount of support, which allows for active engagement and a greater sense of control and mastery over their self and their environment. Activities such as weekly hydrotherapy, allow the opportunity for social connection with family members who often choose to come along, allowing the opportunity for husband and wife to reconnect.

Pin on your notice board

Alzheimer's Queensland Services and Contacts

www.alzheimersonline.org

Helpline

1800 639 331

Open 24 hours a day, 7 days a week.

Free call from landline and public phones.

Or email: helpline@alzheimersonline.org

For information and emotional support for people with dementia, staff and anyone interested. The Helpline has a database or services in Queensland to provide information and referrals.
Call for free information
e.g. fact sheets or brochures to be mailed out.

AQ Rehab

In home - Physiotherapy
Occupational Therapy
Speech Therapy
1800 180 023

Respite and Care Services

Seven days per week including:

- Centre Based Day Respite
- Overnight Respite
- Respite for Working Carers
- Emergency Respite
- Personal Care
- Home Maintenance
- Allied Health
- Social Support

Multi-Service Respite Centres located at:

- Gordon Park
- Mt Gravatt
- Ipswich
- Toowoomba

Residential Care

- Garden City Aged Care Services
- Rosalie Nursing Home
- Windsor Aged Care Services

Call the Helpline for vacancies
for permanent and respite care

Carer Support Groups - 2015

Providing information and support for those caring for a friend or family member with dementia.

Toowoomba: 1st Monday of every month
1.30pm – 3.30pm: Jacaranda Room, Grand Central Shopping Centre, Toowoomba
3 Aug, 7 Sep, 12 Oct (NB: 2nd week due to public holiday), 2 Nov, 7 Dec

Qld Wide Telephone Support Group
Last Wednesday of each Month 1.00pm – 2.00 pm:
AQ organises telephone link up at no cost to participants
29 Jul, 26 Aug, 30 Sep, 28 Oct, 25 Nov

Evening: 2nd Wednesday of every 2nd month
6.00pm – 8.00pm: 47 Tryon St, Upper Mt Gravatt
9 Sep, 11 Nov

Newmarket: 1st Thursday of every month
10am – 12 noon: LifeTec, Cnr Enoggera & Newmarket Rds, Newmarket
6 Aug, 3 Sep, 1 Oct, 5 Nov, 3 Dec

Ipswich: 3rd Wednesday of every month
10.00am – 12 noon: Calvary Baptist Church, 83 Chermside Rd, Ipswich
15 Jul, 19 Aug, 16 Sep, 21 Oct, 18 Nov, 16 Dec

Redcliffe: 1st Thursday of every month 2pm – 4pm:
Redcliffe Library Meeting Rooms, 476 Oxley Ave, Redcliffe
6 Aug, 3 Sep, 1 Oct, 5 Nov, 3 Dec

Mt Gravatt: 1st Friday of every month
10am – 12 noon: 47 Tryon Street, Upper Mt Gravatt
7 Aug, 4 Sep, 2 Oct, 6 Nov, 4 Dec

Weekend: 2nd Saturday of every 2nd month
10am – 12 noon: LifeTec, Cnr Enoggera & Newmarket Rds, Newmarket
8 Aug, 10 Oct, 12 Dec

For further details or to register please contact the Dementia Helpline.

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