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**ISSUE 6**
Dementia Collaborative Research Centre: Assessment and Better Care Outcomes
Professor Henry Brodaty

Congratulations to the 15 successful recipients of NHMRC Dementia Research Grants (see http://www.nhmrc.gov.au/funding/funded/_files/dementia%20grants%20rnd%202.pdf). The research funded was broad in scope. From our DCRC, Victor Vickland will develop and evaluate a computer model for management of behavioural and psychological symptoms of dementia; Lee-Fay Low will investigate dementia literacy in people of Greek, Italian, Chinese and Australian descent; Dimity Pond will extend her study of how to improve GP identification and management of dementia; and Lynn Chenoweth will conduct a randomised controlled trial of the effects of person centred care versus person centred environment versus both or neither. Our centre also has links to Maria Fiatarone Singh, Gavin Andrews and Dr Julian Trollor.

We applaud developments federally. The new government has indicated continuing strong support in the area of dementia related research and care with a particular focus on preventative approaches to chronic conditions including dementia; and the Minister for Ageing, Justine Elliott, has convened the Dementia Advisory Group, co-chaired by Sue Pieters-Hawke and Sallyanne Atkinson, with strong consumer involvement.

Credit: Britta Campion

Dementia Collaborative Research Centre: Prevention, Early Intervention and Risk Reduction
A/Professor Marc Budge

In February 2008, our centre organised a Critical Analysis Day, held at the National Ageing Research Institute, Melbourne. This was an opportunity for our centre members to gather to discuss progress on individual projects in the broader context of our centre and the other DCRCs. There were 22 participants including our centre members and invited guests, all senior clinicians/researchers. Members summarised their work and highlighted points of contention, concern or capacity. Other members, and particularly the invited guests, then provided valuable critique regarding the projects in train. Importantly, linkages between both DCRC and non-DCRC studies and other research entities were explored. In doing so, opportunities for collaboration, synchronisation or future discussions were identified and are now planned. This was evident across all the themes including risk factor reviews, biomarkers, brain imaging, modelling and translation into practice.

The success of the day was echoed particularly by our consumer representative, Patty Hodder, who said that the day had given her a much clearer picture of the work, as well as the challenges of our centre. Given the positive responses from those participating, we plan to repeat the event later this year with even more time allocated to how the “products” of the projects can be disseminated for maximal impact on practice.

Dementia Collaborative Research Centre: Consumers, Carers and Social Research
Professor Jenny Abbey

The DCRC-CCSR is increasing speed as some projects are being completed, reports have been written and new projects started. Project outputs that are available on the DCRC website are listed on page 6 of this newsletter.

Congratulations are sent to Wendy Moyle, from Griffith University, one of the DCRC-CCSR Nodes, who was successful in winning an NHMRC Dementia grant to study the effects of music in Residential Aged Care Facilities.

We welcome two new staff to the DCRC-CCSR. The profiles of Susi Wise and Sue Gledhill will be included in the next report.

Just a reminder, Alzheimer’s Australia produce the Dementia News, a weekly electronic newsletter sent out to professionals and consumers working or dealing with dementia. The aim of this service is to inform readers about the most current media articles on dementia research and treatment. Alzheimer’s Australia’s Research Assistant analyses media and original research papers before presenting a selection of that week’s news items, integrating reported information with a brief value analysis. Information from this is also available in Alzheimer’s News – the most comprehensive electronic news service read by professionals and consumers.

http://www.alzheimersupport.com/bulletins/subscribe.cfm
Much has been made of the challenges stemming from the ageing of the general population, both in Australia and internationally. A similar, but arguably more dramatic ageing phenomenon is being witnessed among the intellectually disabled population in developed countries. Increased longevity in this special population probably has multiple origins; especially influential are improvements in general and medical care. For example Irish Health Research Board statistics show that from 1974 to 2002, the proportion of individuals with intellectual disability increased by more than 3 ½ times for those aged between 35-54 years, and about 2 ½ times for those over 55 years. These dramatic increases are likely to be mirrored in most developed countries and eclipse those projected for the general elderly population in all but selected very old groups. There are many implications of an ageing intellectually disabled population. This brief article highlights three areas: general health, dementia risk and carer issues.

In Australia, adults with intellectual disabilities have access to general services including medical care. However, availability of services designed to specifically meet the needs of adults with intellectual disability is often limited, and services relating to both ageing and intellectual disability are almost non-existent. This is important as some conditions associated with intellectual disability can cause specific medical health problems that manifest later in life, e.g. hearing and visual impairment in Down syndrome, and cardiovascular disease and diabetes in Prader-Willi syndrome. Knowledge of age-related health implications can assist carers and health professionals in early detection or even prevention of some complications. Increased life expectancy of adults with intellectual disability brings with it other challenges. Studies suggest that in comparison to the general population, dementia may be more common among the intellectually disabled. A recent study of intellectually disabled adults suggested that Alzheimer’s disease was about 3 times more common than in the general population. Certain groups are especially at risk: for example, most individuals with Down syndrome over the age of 40 years will have identifiable brain changes of Alzheimer’s disease, and about half of these individuals will develop clinical manifestations of the disorder by their sixth decade. Further studies are required to improve the accuracy of diagnosis and establish treatments for dementia in individuals with intellectual disability.

In clinical practice, it is not uncommon to encounter a family in which an elderly parent continues a role as the primary carer for their ageing child with intellectual disability. This ongoing role brings unique challenges to all individuals concerned and to health professionals. Some of these issues relate to the impact of illness or incapacity of the aging parent carer. Another concern is the changing role experienced by intellectually disabled individuals as they support ageing parents. Occasionally both generations experience age-related issues at the same time. For a good review of physical health issues, aging and intellectual disability see the WHO document.

Finally, as with the general population, it is important to view ageing as a natural and positive life experience for intellectually disabled individuals. This is well summarised on page 7 of the WHO Summarative Report relating to healthy ageing in adults with intellectual disabilities (see http://www.who.int/mental_health/media/en/20.pdf)

“……it is important to underline the fact that many ageing persons with intellectual disabilities may be just as healthy as other older persons without life-long disabilities.”

With the ageing of the Australian population and an improving level of general health, the rapidly rising number of people with dementia means we are facing the prospect of a population where many have healthy bodies, but damaged brains. This phenomenon is already showing up in the increasing number of people in Residential Aged Care Facilities (RACFs) with some form of cognitive impairment needing high level care.

The result is that many RACFs are becoming de facto ‘hospices’ needing to provide palliative care for a large proportion of their residents. The concept of palliative care, inherited largely from its use in late-stage cancer cases, needs to be adapted to fit this new need. Sadly, very few RACFs have suitable models of care in place, or well trained staff capable of delivering this new kind of palliative care.

A palliative approach to symptoms such as pain, dysphagia and recurrent infections has been demonstrated to improve comfort and quality of life for people with end-stage dementia. Although guidelines for implementation of palliative care in aged care facilities have been produced, published and distributed to all RACFs, there are strong indications that staff find it very difficult to implement these without further guidance.

Research undertaken by DCRC-CCSR sought to develop, trial and evaluate a structured model of multi-disciplinary palliative care for people with end-stage dementia, using the Australian Palliative Aged Care guidelines. The model was heavily based on the use of a multi-disciplinary palliative care case conference, involving a General Practioner (GP), using the enhanced primary care guidelines and financial incentives under the Enhanced Primary Care for GPs. The case conference set out in a structured manner a plan for an ongoing palliative approach when family, staff and the GP felt a resident with dementia was moving towards the end of their life.

Following the case conference the families felt satisfied that arrangements were in place to ensure the person with dementia would be free from pain and treated with dignity and respect. In all cases family members asked for no extraordinary measures to be put in place, but to manage their relative’s pain, preserve their dignity and let the inevitable death happen. Staff expressed satisfaction that plans were in place for the difficult decisions that may arise regarding feeding, weight loss, infections and control of pain. They felt relieved of the need to implement futile treatment and care.

Other results showed that the staff felt the time up to and including the resident’s deaths was managed well, the family felt pleased that they had been involved in the planning before death and the GPs reported that RACF staff had handled the deaths in a very professional manner.

Documentation from this project to assist RACFs planning for palliative care for people with dementia is presently being validated. Draft copies are available at http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/dcrc3_Projects#palliative and comments are welcome.


The BPSD (Behavioural and Psychological Symptoms of dementia) node has provided a summary of the literature review, a consumer summary, tips for clinicians (as below) and a table of relevant studies. Download all of these from http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/BPSD.

- Most psychosocial treatments involve some element of social attention (spending time with residents, speaking to them and engaging in an activity) that can account for all or most of the treatments’ apparent benefits in reducing challenging behaviours. Caregivers are often not interested in this distinction. If a simple, enjoyable treatment “works”, that is all that matters. Researchers are still keen to identify treatments that work better than social attention, or that employ social attention in a way that maximises its benefits.

- This review suggests that certain treatments work better than social attention. These include aromatherapy with lavender and lemon balm, bed baths, person-centred bathing, preferred music, one-to-one social therapy, simulated family presence and muscle relaxation training. Some treatments are easy to implement (e.g. aromatherapy although essences of pure oils are needed): others are more elaborate and time-consuming (simulated family presence). Simple, readily implemented interventions are likely to prove more popular in residential aged care facilities.

- Evidence suggests that psychosocial treatments work best when they are adapted to individuals’ interests and abilities. For people in residential care, family members can provide useful information about previous hobbies and interests. Observation will also show which treatments elicit the best response.

- Most psychosocial treatments work for relatively short periods of time. This is a limitation when potentially hazardous behaviours are persistent or when caregivers are unavailable (e.g. at night). Psychiatric medications might prove more useful in these circumstances. Medications are likely to prove more useful than psychosocial treatments when challenging behaviours stem from pain; severe, persistent depression, or psychosis. Psychosocial treatments cannot replace carefully prescribed analgesics, antidepressants and antipsychotics.

- Most challenging behaviours are not persistent. Many arise for brief periods at predictable times (e.g. bathing). Psychosocial treatments might prove most helpful at these times.

- It is helpful to map changes in behaviours over time to check if a treatment is working. There is no commonly agreed tool to assist with this at present.

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As DCRC projects are being completed, reports and summaries will continue to be made available on the DCRC Website (www.dementia.unsw.edu.au). In addition to the projects introduced on page 3 and 4, the following project outcomes are now available:

**Study in relation to the use of PEG tubes for people with dementia:**


**Trial of Community Care Model:**


**Summary of the systematic Literature Review examining oral liquid nutritional supplements for people in residential aged care facilities:**


**Implementation of a Palliative Approach for people with dementia in RACFs which consist of a detailed report, Palliative Care Procedure, Flowchart, Draft Tools and recommendations for clinicians:**


**Recommendations for Clinicians in Acute Care Facilities in managing delirium and a link to Clinical Practice Guidelines:**


**Recommendations for managing pain for people with severe dementia living in residential aged care facilities**


**Comments on the above documents are invited. Please contact Dr. Sandy Sacre at s.sacre@qut.edu.au or ph: 07 3138 5772**

**Summary of literature review covering diagnosis, assessment and management of dementia in general practice:**

http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/GeneralPractice

**Report on Four focus groups of GPs and practice nurses, examining current and proposed practice in dementia assessment, diagnosis and management:**

http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/GeneralPractice

**Summary of systematic Literature Review: Competency standards for dementia care:**

http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/Nursing

**Summary of systematic literature review: Attracting and retaining nurses in aged and dementia care:**

http://www.dementia.unsw.edu.au/DCRCweb.nsf/page/Nursing

More links, clinician tips and reports will be posted soon. Keep your eyes peeled!
The Alzheimer's Australia NSW Memory Van helps raise awareness in regional NSW on the importance of brain health and dementia risk reduction.

Launched in September 2007 at the Dementia Awareness Week Symposium in Newcastle, the Alzheimer's Australia NSW Memory Van is a mobile education resource that travels state-wide providing local communities with dementia specific information designed to help educate and assist people living with dementia, their carers and health professionals.

Successfully funded by the HBOS Australia Foundation, the Alzheimer's Australia NSW Memory Van is fully equipped with Help Sheets, Fact Sheets, DVD & video resources and Nintendo Brain Games. An Alzheimer's Australia NSW Trained Educator travels to NSW regional areas with the Memory Van providing advice on courses and services provided by Alzheimer's Australia NSW. Generally, The Memory Van will set-up at local retirement facilities, community centres, schools and shopping centres in regional NSW on scheduled trips, but The Memory Van is also available for bookings from organisations requiring a presence of these resources at events and health related expos.

During March and April 2008, The Memory Van is scheduled to attend local events in North Western NSW and is visiting the towns & surrounding areas of Moree, Narrabri and Armidale.

For more information about when the Alzheimer's Australia NSW Memory Van is scheduled for your area or, if you would like to make a booking for The Memory Van, please email education@alznsw.asn.au or call the Alzheimer's Australia NSW National Dementia Helpline on 1800 100 500 or visit our website www.alzheimers.org.au.
AAR is happy to be offering a wide range of research grants in 2008 including travel grants, grants focusing on dementia care and grants for new researchers and is encouraging quality applications from all around Australia:

**Research Grants**
- 4 AAR Dementia Research Grants for new researchers of $20,000
- Hazel Hawke Research Grant in Dementia Care of $20,000

**Travel Grants**
- Rosemary Foundation Travel Project Grant of $10,000
- Rosemary Foundation Travel Stipend Grant of $5,000

**Postgraduate Scholarships**
- Hunter Postgraduate Research Scholarship into the Causes of Alzheimer’s Disease ($23,000 per year for 3 years)


Application forms and further information can be found at [http://www.alzheimers.org.au/content.cfm?topicid=250](http://www.alzheimers.org.au/content.cfm?topicid=250)

If you have any questions please contact:
Dinusha Fernando
Email: aar@alzheimers.org.au
Phone: (02) 6254 4233
Alzheimer’s Australia Research
PO Box 4019
Hawker ACT 2614

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**DCRC BABY NEWS…**

We are very happy to announce the birth of Isla Yvonne, first daughter of A/Professor Victoria Traynor and husband Gideon.

This cute little baby was born on 13th Feb weighing an impressive 8lb 2oz.

Congratulations and best wishes from all of us at the DCRCs!

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**Have you heard about Alzheimer’s Australia Research’s 2008 Dementia Grants Program?**

AAR is happy to be offering a wide range of research grants in 2008 including travel grants, grants focusing on dementia care and grants for new researchers and is encouraging quality applications from all around Australia:

**Research Grants**
- 4 AAR Dementia Research Grants for new researchers of $20,000
- Hazel Hawke Research Grant in Dementia Care of $20,000

**Travel Grants**
- Rosemary Foundation Travel Project Grant of $10,000
- Rosemary Foundation Travel Stipend Grant of $5,000

**Postdoctoral Fellowships**
- AAR Post-doctoral Fellowship ($90,000 per year for 2 years)
- 4 Viertel Foundation Postdoctoral Fellowships in Dementia ($45,000 per year for 2 years with payments matched by applicants’ institution)


Application forms and further information can be found at [http://www.alzheimers.org.au/content.cfm?topicid=250](http://www.alzheimers.org.au/content.cfm?topicid=250)

If you have any questions please contact:
Dinusha Fernando
Email: aar@alzheimers.org.au
Phone: (02) 6254 4233
Alzheimer’s Australia Research
PO Box 4019
Hawker ACT 2614
Call for Poster Abstracts

CLOSING DATE: 5pm Friday 13 June 2008
Posters will be displayed on both days (18th & 19th September) and the presenting author should be by their poster between 12.30pm - 1.30pm on the 19th. Six abstracts each will be chosen for a five minute oral presentation in the categories Biomedical Research, and Psychosocial Research on the 18th & 19th of September. A prize will be awarded to the early career researchers (up to 5 years after PhD submission) with the most outstanding presentation for each category.

How to Submit

Abstract submissions are to be received no later than 5pm Friday 13 June 2008. Please email all abstracts, full contact details of the presenting author including whether they are an early career researcher and whether the abstract falls into the Biomedical or Psychosocial category to:

dementiacrc@unsw.edu.au

Compliance to the specifications is imperative - any abstract that does not comply with these specifications will not be accepted for review. All submitting authors will be notified of the results of the review of abstracts by 27 June 2008.

For further information or queries, please contact:

Dementia Collaborative Research Centre  
Assessment and Better Care Outcomes  
45 Beach St  
Coogee NSW 2034  
Phone: 02 9385 9060  
Fax: 02 9385 9075  
Email: dementiacrc@unsw.edu.au  
Website: www.dementia.unsw.edu.au

Guidelines for Poster Abstract Submission:

Title
The abstract title should be short, informative and contain the major key words. It should be in upper case, Arial, BOLD, 12 pt size, and right and left justified.

Authors
Abstract Titles should be followed by the authors' last name and first initial (with the presenting author in bold). Superscript numbers must be used to indicate the author's institution, followed by city and state (in this order). Do not include degrees or professional titles (e.g. Dr, Prof., etc).

E.g.
SmithB1, Pattermore M1,2, Ward L2
1University of Sydney, Sydney, NSW
2University of Queensland, St Lucia, QLD

Abstract format: Microsoft Word, Arial font, justified body of text. Maximum of 250 words.

Your Poster Abstract should include the following:

Background: the study objectives, the hypothesis to be tested, or a description of the problem;

Methods: method(s) used or approach taken;

Results: specific results in summarized form (with statistical analysis if appropriate);

Conclusions: description of the main outcome of the study. All abstracts should disclose primary findings and avoid, whenever possible, promissory statements such as 'experiments are in progress' or 'results will be discussed'.
<table>
<thead>
<tr>
<th>Date</th>
<th>Host Centre</th>
<th>Name</th>
<th>Organisation</th>
<th>Topic</th>
<th>Time Event Code</th>
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<td>Wed 27th Feb</td>
<td>NSW Host (VC in QLD)</td>
<td>Professor Wendy Moyle</td>
<td>Griffith University Research Centre for Clinical and Practice Innovation</td>
<td>Complementary Therapies and Persons with Dementia</td>
<td>1615-1730 (NSW) 1515-1630 (QLD) [GL 08/01]</td>
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<td>Tue 18th Mar</td>
<td>QLD Host (VC in NSW)</td>
<td>Assoc. Professor Marc Budge</td>
<td>Australian National University Department of Geriatric Medicine</td>
<td>ANDI Project: From the Clinician and Consumer Perspective</td>
<td>1615-1730 (NSW) 1515 - 1630 (QLD) [GL 08/02]</td>
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<td>Mon 28th Apr</td>
<td>NSW Host (VC in QLD)</td>
<td>Dr Adrienne Withall</td>
<td>University of New South Wales Dementia CRC (Assessment and Better Care Outcomes), VENUE TBC</td>
<td>Younger Onset Dementia</td>
<td>1745- 1900 (NSW &amp; QLD) [GL 08/03]</td>
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<td>Wed 28th May</td>
<td>NSW Host (VC in Qld)</td>
<td>Dr David Lie</td>
<td>Aged Care Mental Health Services Princess Alexandra Hospital (Brisbane)</td>
<td>Streamed Technology as an Adjunct to Dementia Interventions</td>
<td>1615-1730 (NSW &amp; QLD) [GL 08/04]</td>
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<td>Fri 13th Jun</td>
<td>NSW ONLY</td>
<td>Professor Dawn Brooker</td>
<td>Bradford Dementia Group University of Bradford United Kingdom</td>
<td>Person Centred Care</td>
<td>1615 - 1730 [GL 08/05]</td>
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<td>Thu 19th Jun</td>
<td>QLD ONLY</td>
<td>Kate Allan</td>
<td>Clinical Psychologist Dementia Positive</td>
<td>Communicating with Persons with Dementia</td>
<td>1615 - 1730 [GL 08/06]</td>
</tr>
</tbody>
</table>

**ALL WELCOME**
Drinks and Canapes to follow

Network with colleagues and update yourself on dementia research activities and evidenced-based practice in dementia care

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NSW Contact for further details
Dr Margaret Wallace
Events Co-ordinator, EADTSC
University of Wollongong
Telephone: 02 4221 5927
Email: mwallace@uow.edu.au

NSW Venue (Host and VC to NSW / Shoalhaven)
Auditorium, Graduate School of Medicine,
Building 26, University of Wollongong
VC: Video Conferencing

QLD Contact for further details
Ms Tracey Dutton
Project Coordinator EADTSC (Qld.)
Room 614 (N Block)
School of Nursing
Queensland University of Technology
146 Victoria Park Road
Shoalhaven – Contact for further details
Dr Alison Wicks
AOSC, Shoalhaven Campus
Ph: (02) 4445 0941
Email: twicks@uow.edu.au

Queensland Venue (Host and VC to NSW / Shoalhaven)
Queensland University of Technology,
Room A105, Block A, Kelvin Grove Campus

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- Training Support
- Skill Development
- Competency
- Assessment
- Scholarships
- Education
Change Champions
Improving the Management of Cognitive Impairment for Older People
Amora Hotel Jamison Sydney
11 Jamison St, Sydney, Australia, 02 4963 5150

17 & 18 April 2008

Lab meeting - Dementia Collaborative
Research Centre - Assessment and Better Care
Outcomes
02 9385 9060 dementiaCRC@unsw.edu.au
http://www.dementia.unsw.edu.au

*Prof. Felicia Huppert
“Happiness and Cognition”

Lab meeting - Dementia Collaborative
Research Centre - Assessment and Better Care
Outcomes
02 9385 9060 dementiaCRC@unsw.edu.au
http://www.dementia.unsw.edu.au

*Zeeshan Shahnawaz & Dr Michael Valenzuela

Hammond Care’s 7th Biennial International Dementia Conference - Finding the Gaps and Maintaining the Passion
Bayside Auditorium, Sydney Conference & Exhibition Centre Darling Harbour
02 8295 0381 conference@dementia.com.au

16 & 17 June 2008

Lab meeting - Dementia Collaborative
Research Centre - Assessment and Better Care
Outcomes
02 9385 9060 dementiaCRC@unsw.edu.au
http://www.dementia.unsw.edu.au

*Dr Brett Garner
"Brain lipid homeostasis as a therapeutic target for Alzheimer’s disease"

Lab meeting - Dementia Collaborative
Research Centre - Assessment and Better Care
Outcomes
02 9385 9060 dementiaCRC@unsw.edu.au
http://www.dementia.unsw.edu.au

*Dr Julian Trollor

Lab meeting - Dementia Collaborative
Research Centre - Assessment and Better Care
Outcomes
02 9385 9060 dementiaCRC@unsw.edu.au
http://www.dementia.unsw.edu.au

*Prof. Jonathan Stone

2008 National Dementia Research Forum
Sydney - Wesley Centre
02 9385 9060 dementiaCRC@unsw.edu.au
http://www.dementia.unsw.edu.au

18 & 19 September 2008

Australasian Consortium of Centres of Clinical Cognitive Research (AC4R)
UNSW, Sydney

3 September 2008

International College of Geriatric Psychoneuropharmacology, (ICGP)Sydney
http://www.icgp.org/

3 - 6 September 2008

Alzheimer’s Disease International Asia-Pacific Regional Conference, Taipei

14 - 15th June 2008

Alzheimer’s Disease International Conference, Singapore
http://www.adi2009.org/

26 - 28 March 2009

Alzheimer’s Australia Conference, Adelaide
June 2009
New Knowledge Transfer Position located at UNSW

To assist the Dementia Collaborative Research Centres in translating their dementia research into practice, the new position of Knowledge Transfer Specialist has been created. The Knowledge Transfer Specialist will be expected to build on the existing communication strategies and develop and implement a comprehensive knowledge transfer plan for the Centres. This position would suit an excellent communicator with health (dementia) knowledge who enjoys working in a dynamic and collaborative environment. Further details can be found at

http://www.hr.unsw.edu.au/services/recruitment/newjobgen.html