Abstracts and presenter details:

(In order of presentation – see Provisional Program)

1. Negative positioning and personal integrity in a competitive resources environment

Tracey McDonald
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Western societies are increasingly judgemental towards any who deviate from patterns of behaviour that serve popular social agendas. The types of ‘group think’ that were anathema to us in the 20th Century seem to have been embraced with fervour over the past two decades with the help of communication technologies. Any future acceptance into general society of people living with disability and mental confusion will require positive repositioning of attitudes and values around living with dementia in mainstream society.

Widespread negative positioning of older adults is a manifestation of ageism where the actions of older people are interpreted in ways that undermine their personal identity and integrity and place them in financial, social and health jeopardy in family and social contexts. Increasing general understanding that some normalised behaviours are actually abusive and need to cease requires an awareness heightening strategy that carefully balances the risks of providing detailed examples of elder abuse with clear statements by leaders that such bigotry has to end.

A strategy for raising awareness of ageism and its consequences has been developed in Australia along with several reports on human rights and systematic abuse of older people’s rights but translating this wisdom into outcomes for people is yet to occur. Widespread undermining of the rights and security of older adults is perpetrated by negative positioning arising from prejudice or competition for resources, and only if thought leaders act in a unified campaign will this situation be stopped. Governments, businesses and social leaders including the media are well positioned to lead the type of social change that has curtailed paedophilia and domestic violence in recent times. Ageism within families and societies is a clear target area for prevention of all types of abuse and improving personal security for all.
2. Generational intelligence and social attitudes towards dementia

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The growing numbers of people living with dementia and increased interest within media and public debate raises the issue of how dementia is perceived in the public domain. While the dominant narrative continues to follow a medical approach, social responses to dementia are becoming increasingly important. These include the effects of fear of dementia amongst the aging population, the experience itself among people living with dementia and the social inequalities that cluster around people living with dementia and their carers. This paper will explore some of the dominant narratives as they exist in public campaigning. By using a Foucaultian approach to voice dominance and power and the relationship between power and knowledge we critically assess the focus of contemporary campaigning in this area. Particular attention will be paid to the intergenerational aspects of messages and audiences as an under researched component. The implications of using a model based on generational intelligence and the degree of understanding between generational groups will be examined as a way to promote change in social attitudes towards dementia in the public domain. This research is sponsored by the Australian Cognitive Decline Partnership Centre (NHMRC-project).

3. The social contract behind brain banking

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Dementia is typically caused by synaptic dysfunction, e.g. in Alzheimer's disease where malfunction of synapses precedes the well-known pathological changes, amyloid plaques and neurofibrillary tangles, by many years. A synapse is a connection between two nerve cells, consisting of a submicroscopic gap across which impulses pass. A single nerve cell can have thousands of synapses. Since there are close to 100 billion human nerve cells, the number of synapses is in the trillions. When and where in the brain synapses form is critically important for learning and memory but we still know very little about the total "connectome" of the human brain. Consequently, much more work is required before we can effectively treat cognitive deficits.

Losing one's memory means losing one's self. Therefore, understanding brain function in health and disease represents a most significant scientific frontier. Yet, direct research on the human brain depends on access to brain tissue. The only way to obtain it is through donations and the process needs to be highly ethical in order to be sustainable, which is mandatory because especially fundamental research is characteristically slow.

Sustainable brain banking is under threat because there is insufficient government support and because human brain tissue has assumed significant commercial value in recent years. The latter is in stark contrast to the donors' motivation behind brain banking, which is not a financial one and thus unrelated to that of conventional banking. A brain donor cannot expect to experience personal benefits from her or his donation and the donation is therefore based on trust that the best possible use will be made of the material. Therefore, conflicts of interest need to be identified and safeguarded against. This paper discusses how a change of social attitudes towards dementia may indirectly support brain research.
4. Do people with early stage dementia experience Prescribed Disengagement®? – A systematic review of qualitative studies

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The University of Sydney

Prescribed Disengagement® is the description of the post-diagnostic and advice given to people after a diagnosis of dementia, that explicitly or implicitly suggests that the person should be slowing down or pulling back from activities. This results in isolation, loss of hope, self-esteem and self-identity. This study reviewed whether Prescribed Disengagement® can be identified in the literature on subjective experiences of people living with early dementia. A systematic search was performed. Inclusion criteria were original empirical qualitative studies published in English that addressed the subjective experiences of living with a diagnosis dementia, participants had to have objectively defined early stage dementia. Thematic synthesis was undertaken. Thirty-five papers involving 373 participants were included. Following a diagnosis, people with dementia struggled with self-identity, independence, control and status, activities, stigma, and how to view the future. Reactions in these areas ranged from active and positive, to negative and passive. Many studies reported participants’ dissatisfaction with the way the diagnosis was communicated. There was insufficient information provided about dementia and limited treatments and support offered. The diagnosis process and post-diagnostic support contributed to disempowerment of the person with dementia, made it more difficult to accept the diagnosis, and exacerbated negative views around dementia. Diagnosis is a key point of disempowerment for people with dementia - disengagement is implied, but not actively prescribed. Research is needed on how to improve the communication of a diagnosis of dementia and to develop post-diagnostic interventions that support people with dementia to live well.

5. Difference, diversity and dementia: drawing on the experiences of older women

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The feminisation of ageing and the intersecting of age and gender have significant and important implications for dementia research and the development of policy and practice. Older women are disproportionately affected by dementia, making up the majority of those living with dementia and the majority of those caring for people with dementia, as paid and unpaid carers. However, generally discussions about dementia pay little attention to the diverse experiences of older women with dementia, older women as informal carers and older women as paid care workers. Older women are also subjected to structural and interpersonal violence and discrimination based on age, gender, ATSI, class, race, ethnicity, sexuality, and disability and face huge challenges such as poverty, homelessness and difficulties accessing employment, health-care and aged care services. This paper reviews and builds on recent research with those affected by dementia that takes gender and the voices of older women into account. Drawing on this review the paper will then focus on how, by including gender and the experiences of older women, researchers and activists can devise and influence research programs, policies and practices and work towards creating a more caring world.
6. Principles into practice: enhancing the expression of personhood in health care

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Quality Jobs Quality Care Project, University of South Australia

This paper commences with the prevailing social ideal of the person being strongly based on the ability to reason. This pervasive ideal has led to what Post calls a ‘hyper-cognitive’ society. Those who do not meet this threshold, as in the case of dementia, become lesser persons socially and often legally. As the majority of persons with dementia are in later life, ageism and paternalism compound the diminished view of the older person with cognitive changes. Stigma, prejudice and stereotypes about the older person with cognitive frailty maintain social norms and practices that diminish those who are vulnerable. These prevailing attitudes are powerful in damaging a person’s self of self, their confidence and ability to exercise autonomy, and leads to external constraints on the options and choices available.

Central to shifts in social norms and stereotypes is that of recognising that autonomy is not absolute, but relational. This includes a broader understanding of ‘the person’ as multi-dimensional and not defined by cognitive ability. It also includes recognising the interdependence of persons, and frailty as a common aspect of the human condition.

Aspects such as stereotypes about the person and subsequent diminished personhood will be illustrated through examples of case studies in a hospital setting, where the ‘problem’ is constructed from within the medical paradigm. Solutions are developed externally to the person, whose voice and personhood is diminished. Often in the midst of changes in health and life transitions, the older person with dementia is particularly vulnerable to others’ values and attitudes. A person-centred approach that respects the whole person and their life meaning is proposed as a way forward.

7. Beyond the biomedical model: Insights into care for people with dementia through a ‘personhood lens’

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Many care providers are not equipped to understand the cognitive and behavioral issues people with dementia experience or how to provide effective, person-centered care.

The Wicking Dementia Research and Education Centre offers a fully online interdisciplinary Bachelor of Dementia Care (BDC) that centers on the biopsychosocial model of health, increasing understanding of the changes occurring in the brain, the behaviors that result, and effective, multi-dimensional person-centered care. In Year 1, 383 students completed Principles of Supportive Care for People with Dementia, investigating person-centered and dignity-preserving care across the trajectory of the condition. In Year 2, students completed a follow-up survey.

A thematic analysis of students’ reflections following the Year 1 unit documented understanding of person-centred care: “I gained understanding of how treating the illness and not the person meant that you were really denying someone’s “person-hood” and acting in unhelpful ways.” “I feel that my understanding of person-centred care and the realisation that people [with dementia] not only have the capability to improve, but also the right to receive the treatment that may allow them to, has changed my practice [and] the way I speak about dementia.” Analysis of students’ (n = 148) responses to the Year 2 survey confirmed their appreciation of the dimensions of autonomy, safety, and comfort in dignity-preserving, person-centred care at all stages of the condition.
Aged care organisations seek to ensure that people with dementia are treated with respect, dignity and understanding. Yet, these values are not easily translated into practice. Using a biopsychosocial model focused on the person not the diagnosis, the BDC presents learning about care through a “person-hood lens.” This encourages students to reflect on their own practices and those of others, and equips them with knowledge to model and enact these values in the direct care setting.

8. How to develop access to dementia-friendly support and information for carers of people with dementia who live at home – all those unpaid/voluntary/family carers

*Maree McCabe*

*Alzheimer’s Australia*

Alzheimer’s Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia poses a unique challenge for Australia due to increasing prevalence, economic costs and social implications. With around 70% of people with dementia living in the community (AIHW 2012), comprehensive community based support is critical to meet the needs of people living with dementia.

While the need for a medical cure continues to drive research and funding, it is vital to simultaneously look at how we can support and assist people in continuing to live well with dementia. Alzheimer’s Australia believes that all communities have the potential to support people living with dementia to maintain independence, dignity, a sense of purpose and to live in an environment of their choosing for as long as possible. This is where technological advancements are making tremendous leaps in assisting people with dementia and their carers. Through various collaborations, AA has designed, developed and implemented several cutting edge technological projects that continue to influence best practice policy around Australia. These include:

- Virtual learning environments like the award winning Virtual Dementia Experience,
- Immersive technology that can let people into the world of the person living with dementia like the just released app, EDIE, (Educational Dementia Immersive Experience, pronounced Eddie) which provides the user with a 360-degree immersive experience that enables them to see first-hand the challenges faced by people with dementia.
- The Virtual Forest project that uses a sensory therapy application designed to improve the quality of life of people living with dementia through the use of video game technology.
- The Dementia-Friendly Home app that uses interactive 3D game technology and provides carers with ideas to make their home more accessible for people living with dementia.

11. Feeling intelligence and dramatherapy with people with dementia

*Joanna Jaaniste*

*Western Sydney University*

We know that later life stages can be some of the most creative in people who have no dementia; for example Goethe, Picasso, Pablo Cassals and Grandma Moses. In dementia, when executive function can be missing, feelings can be addressed creatively. Through the arts, touch and bodily expression, people with dementia show that they are highly creative and have strong feeling lives. Engaging these qualities and using techniques such as play and body work, it is possible to give people Quality of Life (QoL) and connection to others and to the world.
In such an enquiry, it is valuable to look at Sue Jennings’ Embodiment, Projection and Role (EPR) as a developmental paradigm for the young child (Jennings, 1999), and simply reverse these for old age as RPE. In this paper, using case studies, I will give examples of how RPE unconnected with notions of infantilisation can work with feeling. Important investigation into dementia and embodiment reframe and deconstruct the linking of cognition with selfhood (Kontos 2012; Kontos and Martin 2013; Jaaniste 2016) and call into question the concept that self-awareness is linked only to pre-dementia cognition.

Results of clinical work using QoL scales will be shared with participants, evidencing triangulation and mixed methodology as helpful in breaking new ground for the many elders who will fall prey to dementia in the next decades.

12. The voices of those with dementia, and their carers: some researchers ARE listening

Susan Kurrle, Joan Jackman, Jennifer Thompson, Sally Grosvenor, Shannon McDermott and Alexandra Nikitas

NHMRC Cognitive Decline Partnership Centre, University of Sydney / Alzheimer’s Australia

Research at the NHMRC Partnership Centre – Dealing with Cognitive and Related Functional Decline in Older People (known as the Cognitive Decline Partnership Centre – CDPC) is focused on key challenges for delivering good quality care for people with dementia and their carers. Those key challenges, and the identification of the CDPC’s initial research projects, were driven by consumers, and then brought to researchers and industry funders as part of a fully collaborative development process. Therefore, the CDPC is a unique collaborative model for delivering research, designed to deliver real outcomes for people with dementia and their carers across the themes: reducing stigma, end-of-life decision making, implementing proven models of care, new approaches to support for informal carers, improved service planning, improving regulations, promoting responsible medication management, creation of up-to-date clinical guidelines, and building quality into the aged care workforce.

As early as 2005, the National Health and Medical Research Council (NHMRC) was reframing the ideologue that consumers are passive participants in research, by expecting grant applicants to give recognition to the Statement on Consumer and Community Participation in Health and Medical Research, and include consumers more broadly in their research. As the inaugural NHMRC Partnership Centre, the CDPC was, from its inception, designed to ensure the consumer Statement was adhered to. Over the last two and a half years the CDPC, with consumers integrally involved at all stages of priority setting, research development, research conduct, and research dissemination of outcomes, has set a new standard for consumer involvement that takes the person-centred approach to research and makes it a reality. With thirty three research activities funded through the CDPC, and findings of the research projects that have already been completed being disseminated widely, the impact of consumer involvement, will be far-reaching for people with dementia and their carers.
13. Understanding the journey better: an exploration of the current “state of play” of the health care journey experienced by people living with dementia and their carers.

Janna Anneke Fitzgerald, Joanne Curry and Angelique Olde Meierink

Griffith University

In Australia, the prediction is that by 2050 more than one million people will be living with dementia (Deloitte Access Economics, 2011). To date, little research has focussed on the impact of interventions on the real lives of people living with dementia and their carers. Our objectives were to: (1) give voice to people with dementia and their carers about their individual journeys in order to understand positive and negative experiences; (2) identify current pathways and roles for the coordination, integration and delivery of care; and (3) identify opportunities for improvement on the current processes in order to optimise effective coordination, integration and delivery of care. Stories were collected during five two day workshops, with 24 consumers and carers, across Australia. This resulted in 18 storyboards. Patient Journey Modelling software (Essomenic) was used to visualise the stories, documenting personal experiences. Opportunities for Improvement were sought from all participants and aggregated into an “ideal state” journey.

This research resulted in a much better understanding of the experiences of people living with dementia and their carers. Several gaps were identified: there is a big delay between symptoms and actual diagnosis, there is little coordination of care across providers, knowledge and clarity of clinical pathways were largely unknown and carer support was reactive rather than proactive. Real impact can be achieved when we know what people with dementia and their carers want. This study outlines the opportunities for improvement desired in the current healthcare journey according to those who live with dementia and their carers. Through using consumer voices, an ideal dementia pathway is being presented on a storyboard indicating dementia is a social and cultural experience.

14. ‘I feel like a tiny ant waving at people walking around’. Perspectives of families living with younger onset dementia (YOD)

Karen Hutchinson and Chris Roberts

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People living with a physical impairment often face marginalization. This has been explained by the social model of disability which helps understandings of the cultural, economic and environmental barriers experienced. However there has been very little utility of the social model in the dementia sector, to include the lived experiences of families living with YOD. The aim is to demonstrate the use of the social model of disability as a theoretical framework to help understand the societal impact on the lives of families with children and young people where a parent has YOD. We conducted a thematic analysis on 26 semi structured interviews with young people, parents living with YOD and parent/ carers using the social model of disability as a theoretical framework to understand how society contributes to their emotional distress and marginalisation.

The results show that family members, not just the person with the impairment report invisibility, disengagement and exclusion from society. The capacity for the family to support each other is influenced by both societal attitudes and discrimination. This creates socially constructed disablement causing social disadvantage and barriers that impact the family dynamics. The interplay between managing individual impairment and whole family disablement contributed to additional emotional distress within the whole family.
We concluded that socially constructed disablement is not isolated to the person living with YOD but affects all family members. There is a lack of family focused approaches which acknowledges the needs of the family as a whole, of which the parent living with YOD is an integral member. It is important for service providers to recognize that a whole family approach is necessary to address both the impairments of cognitive decline and the social disablement of the whole family.

15. The organisation of risk and innovation in dementia care: strategies used by different levels of provider agencies

Simon Biggs and Ashley Carr

School of Social & Political Sciences, University of Melbourne

This paper presents research on the role and effects of regulation on dementia care. It shows how regulation, and the way in which aged care providers respond to regulatory demands, creates a social space for the conduct of care. The paper begins by outlining how the tightly controlled and regulated residential care environment encourages aged care providers to develop strategies as a means to provide a specific kind and quality of dementia care. Drawing on interviews with aged care senior managers, facility managers and direct care workers, these strategies are shown to have different practical implications depending on the level of the organisation. The strategies employed by care workers for instance are largely interactional, an examination of which shows how care proceeds in light and often in spite of regulatory requirements. Here the challenging nature of dementia care, particularly the importance of self, well-being and care quality, are negotiated through various communicative and relational techniques. These are often contextually and individually specific, suggesting a model of regulation that stipulates limits and provides guidance, but enables significant degrees of flexibility and autonomy. The policy and practice implications of this approach to regulation, it is argued, promotes facilitative rather than restrictive care spaces and relations.

16. Planning for the rest-of-life, not end-of-life: Reframing advance care planning (ACP) for those with dementia

Gail Yapp, Craig Sinclair, Adele Kelly, Kathy Williams, Ingrid Amgarth-Duff and Meera Agar

Hammond Care, Sydney

Advance care planning (ACP) has evolved from a medical model due to concern that the medical interventions likely to be given when people cannot make their own decisions may not be what the person would have chosen for themselves. Semi-structured interviews with people with experience in ACP from a range of community, health and aged care settings from across Australia explored their views of what was needed to improve the implementation of ACP for those with dementia.

Interviews with 82 participants revealed different perspectives on ACP, in part influenced by the setting of practice of the informant and their underlying philosophy of care. In the acute setting in particular, health professionals are looking for certainty and authority to inform what medical interventions should/should not be undertaken, leading to a predominance of models which are medically based approaches to ACP, often focussed on end-of-life decision-making and interventions. Extensive criticism of the biomedical approach to ACP came from all settings for a diverse range of reasons. Other approaches to ACP, fitting with a psychosocial philosophy of care were considered more suitable, especially for those with dementia. These included family-centred and person-centred approaches which focussed on or incorporated consideration of values and cultural, spiritual and lifestyle issues. These approaches were more likely to be suggested by those in aged and palliative care settings. Respondents in all settings identified the relational aspects of ACP with the emphasis that what mattered most were conversations, on valuing and informing the rest-of-life, not just end-of-life; and the appointment of a trusted substitute decision-maker.
ACP models need to consider a broader social, personal and community context to ensure that outcomes achieved don’t purely focus on medical decision-making, but on a broad range of areas identified as important by people with dementia and their caregivers.

17. Creating age friendly communities: promoting intergenerational care programs as a way of tackling social responses to people living with dementia

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Griffith University

Intergenerational care programs provide older adults and children care and social support programs, in the same setting, for a specified period of time (Newman et al., 1997). Intergenerational care programs have psychological benefits for older adults by creating a sense of purpose (Chen, 2009; Goswami, Köbler, Leimeister, Krcmar, 2010), enhancing the dignity of older people and changing community expectations of existing care and support services available to older people living with dementia (Skropeta, Colvin, and Sladen, 2014). However, while intergenerational care programs are established globally, they are still in their infancy in Australia. This study investigated the feasibility of creating formal intergenerational care programs in Australia to identify preferred programs and people’s willingness to pay for such programs.

Preliminary results from 928 participants (176 parents, 127 carers of older adults, 64 adult care recipients and 561 others) suggest that 71% would consider using an Intergenerational Care service. Of those that ranked their preference for the models presented (n=339), over half (54%) preferred a shared campus model, where child care and aged care are co-located. For this they were willing to pay $8.31 more than current services for this model, although this varied by the type of participant (e.g. parent, carer, older adult, general public). A further 24% preferred a visiting campus model, where each centre is located separately and care recipients visit each other during the formal part of the program. Users were willing to pay on average $7.86 more for this service. The remaining, 15% of respondents preferred separate aged care and child care models and 10% preferred none of the options. The reasons for inclusion or exclusion of this program varied. These findings suggest that intergenerational care may be a feasible model in Australia as one way of tackling the social response to people living with dementia.

18. Experiences of decision-making and advance care planning by people with dementia and their care-partners: a relational perspective

Craig Sinclair, Romola Bucks, Kathy Williams, Meredith Blake, Sue Field, Josephine Clayton, Sascha Callaghan, Helen Radoslovich, Kirsten Auret, Susan Kurrle

The Rural Clinical School of Western Australia

Neo-liberal understandings of chronic illness, its associated stressors and adaptive approaches to coping have typically taken an individualist perspective. Charmaz (1983) describes how chronic illness challenges one’s ‘sense of self’, through loss of identity, loss of roles and ongoing existential threat. Influential theories of illness-coping (e.g. Lazarus & Folkman, 1984) have similarly defined coping from an individual perspective, with family members and social networks seen as reservoirs of support, rather than active agents in a relational landscape. More recent approaches have explored dyadic perspectives towards illness-coping (Berg & Upchurch, 2007). This perspective proposes that dyads may jointly ‘own’ an illness experience, with implications for appraising and addressing illness-related stressors.
Dementia is a chronic, neurodegenerative condition, with a trajectory of cognitive and functional decline that present patients and families with challenges to their established roles and methods of communication, and implications for how they make decisions and plan for the future. Advance care planning (ACP) has been proposed as a way of promoting ‘individual autonomy’ in the face of progressive disease. However, the low uptake of ACP by people with dementia, along with ethical concerns about impaired decision-making capacity, challenges the neo-liberal discourse of individual autonomy. In the absence of ACP, family members are often required to make critical decisions on behalf of a person with dementia, often with minimal information about the person’s wishes. Neither of these approaches appear well-matched to the relational experience of dementia.

This study aims to understand the experiences of people living with dementia and their care-partners, towards decision-making and ACP. In-depth, dyadic interviews are used to explore the utility of a relational perspective on decision-making and ACP in dementia. Based on preliminary results, we propose that relational perspectives may better explain existing data, and inform more family-centred approaches to decision-making and ACP in the context of dementia.

19. Changing selves: developing a relational approach to dementia

Gaynor Macdonald
Anthropology, University of Sydney

The medicalisation of dementia and the almost frenzied search for the cure (however desirable and necessary) risks avoiding the conversation we all need to have: what is ‘life’ about and how should we live it well. Dementia is understood in different ways, and these ways influence approaches to care. Behind these understandings are cultural ideas that need to be brought to the forefront. A barrier to reframing dementia as one of life’s experiences is the way in which the ‘persons’ of modernity – the liberal/neo-liberal worlds of capitalism that most of us are familiar with – are conceptualised. How we think of ourselves as ‘selves’ and ‘persons’, as ‘individuals’ or ‘relational beings’, how social value is determined and how this changes over the life course, who constitutes the ‘us’ or the ‘other’ – all such ideas are embedded in cultural values that are deep-seated and usually taken-for-granted. Drawing on anthropological understandings of different ways of being persons in the world, I argue that these taken-for-granteds can be – and need to be – challenged if we are to create a more caring society in which the whole gamut of human experience can be valued and lived with. We have shown that we can change attitudes towards gender, disability, race – albeit the struggle to do so is ongoing. We need to bring similar insights and strategies to thinking about the life cycle from birth to death, including ageing; to the experiences of strength and vulnerability that beset everyone; to our inherent interdependency; and our mortality. Dementia seems to bring all these life challenges to the fore: inviting us to rethink the way we think about ourselves as interdependent social beings.

Workshop Discussant

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