

Institution: University of the West of Scotland		
Unit of Assessment: 3: Allied Health, Dentistry, Nursing and Pharmacy		
Title of case study: Improving quality dementia care and promoting positive living		
Period when the underpinning research was undertaken: 2011 - 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Prof Debbie Tolson	Professor	2013 - 2020
Dr Louise Ritchie	Reader	2013 - 2020
Dr Margaret Brown	Senior Lecturer	2004 - 2020
Dr Anna Jack-Waugh	Senior Lecturer	2004 - 2020
Dr Rhoda MacRae	Senior Lecturer	2014 - 2020
Prof Pauline Banks	Professor	2009 - 2014
Prof David McGillivray	Professor	2010 - 2020
Ms Hazel McWhinnie	Lecturer	2005 - 2018
Prof Graham Jackson	Emeritus Professor	2013 - 2017
Dr Karen Watchman	Senior Lecturer	2013 - 2016
Period when the claimed impact occurred: 2013 - 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Fifty million people worldwide (850,000 UK, 90,000 Scotland) have dementia. In the absence of effective treatment, the WHO Global Action Plan promotes quality care and positive living; key domains of our research impact. Our research has informed new quality improvement systems, changing practice and practitioner education as far afield as Portugal and Mexico, and challenged Scottish Government to recognise advanced dementia needs as healthcare. We have re-positioned advanced dementia as a distinct phase associated with complex dementia-specific palliative care needs. Using our findings to expose inequalities, a major campaign for fair dementia care has secured 15,000 signatories, catalysed political debate and secured Scottish Government commitment to review. Our dementia in employment research revealed a previously hidden problem, giving impetus to training for dementia positive employment practice driven by national agencies and trade unions, benefiting the lives of the 40,000 working-age people in the UK with early onset of dementia.</p>		
2. Underpinning Research		
<p>Led by the Alzheimer Scotland Professor of Dementia (Tolson), the Dementia Research Team, along with 14 doctoral students, have developed a pioneering programme of research to inform and propel dementia positive practices and quality care.</p>		
<p>EMPLOYMENT: Approximately 40,000 people in the UK are diagnosed with dementia whilst of working age, but little attention is afforded to the impact this has on employment. Led by Banks and Tolson, with Ritchie our influential pioneering case study research on dementia and employment was funded by the Alzheimer's Society [3.A, 3.B]. Importantly, this research highlighted that people with dementia can continue to work post-diagnosis; however, there are inequalities in employment experiences, with many losing employment pre or at the point of diagnosis and unable to access support. As co-investigators in a follow-on study, Ritchie and Tolson investigated employers' perspectives of dementia in the workplace, funded by Carnegie Trust [3.C]. Mixed method surveys and interviews with employers highlighted significant gaps in knowledge and understanding of dementia and its effects in the workplace. Ritchie led our third ground-breaking study providing a theoretical perspective on dementia in the workplace, undertaking a secondary analysis of interview data using a theoretical lens. The findings of this study outline the range of personal resources, supports and environments required to enable positive employment-related experiences and practices for people with dementia.</p>		
<p>ADVANCED DEMENTIA: Concerned by reports of variation in the quality of dementia care and dementia education around the world, we focussed our attention on the advanced stage of the illness, a term much used in practice and spoken about by concerned family carers. The Dementia Palliare project, funded through Erasmus+ Key Action2 funding [3.D] was led by Tolson with</p>		

MacRae, Brown, Jack-Waugh, Watchman and Jackson at UWS collaborating with teams from seven European countries. Palliare involved a series of studies to understand and describe the complexity of care needs associated with advanced dementia and develop educational interventions. Through an integrative literature review, 22 comparative person-centred case studies, policy analysis and mapping of current educational and national workforce development programmes, **our research challenged current conceptualisations** of advanced dementia and the preoccupation with death and dying. Highlighting that people can live for up to 10 years with advanced illness, our research redefined advanced dementia, developing a dementia-specific palliation approach focussed on living the best life possible; an approach we called Palliare. Findings were synthesised into a best practice statement (BPS) setting out what practitioners and family carers need to know to deliver high-quality care and to support people with advanced dementia to live the best life possible. A consensus conference in Prague and public consultations facilitated by national Alzheimer Associations informed the refinement of the BPS and its subsequent presentation as an interprofessional learning framework. Project outputs have been translated into seven different languages.

DEVELOPING CARING INTERVENTIONS: Through our Palliare research, we revealed a weak evidence base for caring interventions suitable for people with advanced dementia. Working collaboratively with practitioners, we explored innovations using enhanced sensory approaches. QNIS and Burdett Trust **[3.E]** funded interventional case study research enabled **Brown and McWhinnie** to collaboratively develop and test an innovative sensory care approach to mealtimes within care homes. This involved replacing passive spoon-feeding at mealtime with the neurologically stimulating hand over hand method, using sensory techniques to stimulate appetite, food recognition and choice. The technique was successful with a range of beneficial outcomes in terms of mealtime enjoyment and sociability, improved food intake and weight maintenance.

In another study, funded by NHS Putting You First with Alzheimer Scotland **[3.F]** led by **Watchman** with **Tolson**, we collaboratively developed and piloted **original individualised sensory care methods** tailored for people with advanced dementia, delivered in partnership with family carers and trained volunteers, in a **novel advanced dementia day-care service**, underpinned by Palliare approaches. This research demonstrated the viability of advanced dementia stage-specific day care and the importance of enhanced sensory care within such a service.

As co-investigator in an AHRC funded mixed-methods study **[3.G]** **McGillivray** created a unique protocol for safe community delivery of football-focused reminiscence groups for people with dementia. Subsequently, we adapted this protocol through the introduction of enhanced sensory reminiscence methods for use with people with advanced dementia. **Watchman** and **Tolson** completed an intervention study with Spanish researchers, to create a model for practice, delivered within day-care and nursing homes in Spain and Scotland, funded by the Spanish Federation of Veteran Players **[3.H]** and Alzheimer Scotland (pilot grant) **[3.I]**.

3. References to the research

3.1 Ritchie, L., Tolson, D., Danson M. (2017) Dementia in the workplace case study research: understanding the experiences of individuals, colleagues, managers and family. *Ageing and Society*. 38(10): 2146-2175. <https://doi.org/10.1017/S0144686X17000563>

3.2 Ritchie, L., Egdell, V., Danson, M., Cook, M., Stavert, J. and Tolson, D. (2020) Dementia, work and employability: Using the Capability Approach to understand the employability potential for people living with dementia. *Work, Employment and Society*. <https://doi.org/10.1177/0950017020961929>

3.3 Hanson, E., Hellstrom, A., Sandvide, A., Jackson, G.A., MacRae, R., Waugh, A. Abreu, W. & Tolson, D., (2016) The extended palliative phase of dementia – an integrative literature review. *Dementia*. 18(1): 108-134. <https://doi.org/10.1177/1471301216659797>

3.4 Tolson, D., Holmerova, I., MacRae, R., Waugh, A., Hvalic-Touzery, S., de Abreu, W., Lillo Crespo, M., Merta, A., Hanson, E., (2017) Improving Advanced Dementia Care an Interprofessional Learning Framework. *Journal of the American Medical Directors Association*, 18(7): 561-563. <http://dx.doi.org/10.1016/j.jamda.2017.03.014>

3.5 Brown, M., McWhinnie, H., McAlister, J., Logan, V., McDowall, M., Booth, J., Heron, K., McIntyre, P., Baylis, M & Banks, P., (2014) Food for Thought: Enhancing dietary preferences for the person with advanced dementia. Report to Funders. The Queen's Nursing Institute Scotland. <https://www.qnis.org.uk/wp-content/uploads/2016/11/Food-for-Thought-Report.pdf>

3.6 Coll Planas, L., Watchman, K., Domenech, S., McGillivray, D., O'Donnell, H., Tolson, D., (2017) Developing Evidence for Football (Soccer) Reminiscence Interventions Within Long-term Care: A Co-operative Approach Applied in Scotland and Spain. *Journal of the American Medical Directors Association* 18(4): 355–360 <https://doi.org/10.1016/j.jamda.2017.01.013>

Grants

3.A Tolson, D., Danson, M., **Banks, P.** *Dementia in the Workplace; the potential for continued employment post diagnosis*, Alzheimer Society, 2013 - 2015. GBP97,961

3.B Ritchie, L., *Alzheimer's Society Dissemination Grant*, Dementia in the workplace. 2017 to 2018. GBP2,500

3.C Stavert, J., Ritchie, L., Danson, M., Egdell, V, **Tolson, D.** *Employers Responses to Dementia in the Workplace in Scotland*. Carnegie Trust for the Universities of Scotland. 2016 to 2018. GBP47,327

3.D Tolson, D., Holmerova, I., **Watchman, K., MacRae, R.,** Hvalič-Touzery, S., Hanson, E. Abreu, W., **Jackson, G., Jack-Waugh, A.** et al. *Dementia Palliare Erasmus + Key Action 2 Strategic Partnerships in Higher Education Development of an interprofessional experiential learning solution: equipping the qualified dementia workforce to champion best practice during the extended palliative care phase of advanced dementia*. European Commission. 2014 to 2016. EUR290,899 (GBP234,678)

3.E Brown, M., McWhinnie, H., McAlister, J., **Banks, P.** *Food for Thought: Enhancing dietary preferences for the person with advanced dementia*. Queens Nursing Institute for Scotland. 2013 to 2014. GBP9,925

3.F Tolson, D., Watchman, K., Brown, M., Jackson, G. *Family caring in advanced dementia; the contribution of enhanced sensory care delivered within a day care setting*. NHS Putting You First with Alzheimer Scotland. 2013 to 2014. GBP19,315

3.G Tolson, D., O'Donnell, H., **McGillivray, D.,** Craig, R., Simmons, H., Stirling, K. et al. *Enhancing Therapeutic Benefits of Reminiscence Work for People with Dementia Harnessing the Heritage of Football*. Arts and Humanities Research Council & Scottish Funding Council Knowledge Exchange Programme. 2011 to 2012. GBP74,994 (GCU led in collaboration with UWS).

3.H Coll-Planas, L., Tolson, D. et al *Spanish Pilot Football Reminiscence*. Spanish Federation of Veteran Players. 2013 to 2014. EUR10,666 (GBP7,901)

3.I Watchman, K., Tolson, D. *Football reminiscence for men with dementia in a care home: A 12 week pilot study*. Alzheimer Scotland Pilot Study Scheme. 2013 to 2014. GBP5,905

4. Details of the impact

Change in practice in the UK, Portugal and the Czech Republic are a direct result of our pioneering work on improving the lives of people living with dementia; promoting positive living.

POSITIVE LIVING: Our dementia in the workplace research has been central to the creation of guidance on 'Creating a Dementia Friendly Workplace' produced by the Alzheimer's Society, which has been received or downloaded by more than 4,000 people across the UK [5.1]. In collaboration with Ritchie and Tolson, the Scottish Trades Union Congress (STUC) with significant international reach, launched guidance for trade union representatives on how to support members who have been diagnosed with dementia whilst in the workplace in June 2016 [5.2a], which was followed up with dementia training for more than 100 trade union representatives in

2016 and 2019. Feedback indicated that the training helped to address misunderstandings about dementia – “*Thought dementia diagnosis meant the person could no longer function from about that point on,*” – and commitments to take positive action – “*Working with health and safety reps on this to ensure correct environmental factors are in place.*” [5.2b] This research has also motivated third and public sector organisations to provide support and training about dementia in the workplace. Age Scotland introduced training directly informed by our research, which has been delivered to 703 people in 63 organisations, including Falkirk Council and Hanover Housing Association. The Dementia Training Co-ordinator credited our research as “*a vital component in the creation of this popular and effective programme.*” [5.3] Direct practice changes as a result of the training are currently being evaluated within Age Scotland.

Our football reminiscence studies and model for practice have inspired and informed the establishment of more than 100 Scottish community football-reminiscence groups. Drawing on our research, Tolson was invited to advise on the establishment and evaluation of the **first baseball-reminiscence league piloted in St Louis, USA**, reported on Fox News in 2014. There are an estimated 5.7 million US citizens with dementia. Since the St Louis pilot, a further five baseball-reminiscence leagues have been established in other states, which have been inspired and informed by our research [5.4a]. Although football-reminiscence groups appeal more to men, baseball-reminiscence groups are reportedly attractive to women and are more gender inclusive. Sustainable community groups like these highlight societal benefits on health and wellbeing, research impact showcased by the Arts and Humanities Research Council in their report (2013) to the UK parliament [5.4b]. Harnessing the legacy of popular sport in this way provides social benefit by addressing loneliness, social isolation in addition to cognitive activity.

QUALITY DEMENTIA CARE: The focus on quality of care has seen results in the UK and internationally. Our Palliare literature review, the first to interrogate what is known and not known about advanced dementia care and care experiences, was cited in the internationally influential **World Alzheimer Report (2016)**. This endorsed our challenge to the preoccupation with end of life, recognising advanced dementia as a continuum involving months and sometimes years of living with complex healthcare needs. Invited keynote presentations at the Global Alzheimer Research and Care Summit (Lisbon 2017), and Europe’s largest long-term care sector conference funded by the ‘Together we change the World Foundation’ in Poland (2019) (1,000 delegates from 31 countries). The focus on advanced dementia was heralded by Polish industry organisers as a new and important direction for the long-term care sector in Europe and a practice-focused call-to-action paper, based on our research, was circulated to 2,000 European care providers in English, Polish and Russian [5.5]. A Professor at the University of Porto testifies to changing practitioner education in Russia inspired by our **state-of-the-art portrayal of best practice** [5.6]. Our advanced dementia research has improved the quality of care for people with advanced dementia in Scotland and internationally. Care provider Erskine has adopted the Food for Thought model, developed and piloted in our research, across its residential dementia care provision in four care homes. The Director of Care explained that they have “*instituted a 10-point sensory meal plan system to achieve an individualised positive mealtime experience, including environment and food presentation changes alongside use of the neurologically stimulating and dignified ‘hand over hand method’ in preference to ‘spoon feeding’*” [5.7]. To date, this approach has directly benefited over 200 residents. Food consumption and body weight stabilisation has been observed. Relatives and staff report increased mealtime communication, signs of sensory enjoyment and improved personal efficacy in independent eating and drinking.

In Portugal, the findings of our Palliare project has led to an increased focus on the care and wellbeing needs of those with dementia in a number of settings; one example is the Hospice Casa de Saude, who have introduced sensory based interventions, and changed practices drawing on our research based description of Best Palliare Practice [5.6]. These care improvements have strengthened focus on living the best life possible and person-centred advanced dementia care. Taking a quality improvement approach to reforming advanced dementia care in nursing homes, the Czech Alzheimer Society [5.8.a] created the *Vážka criteria* and quality certification system based on our Palliare Best Practice Statement (BPS); to date, 70 social care facilities have demonstrated improvement and compliance. Additionally, Hospital HLA Visteraherosa has introduced Palliare outcomes for the first time to improve advanced dementia care within a Spanish hospital [5.9].

IMPROVED DEMENTIA EDUCATION: Our Palliare research has changed or introduced new advanced dementia education in universities internationally, as well as in local communities. At UWS, we have created new modules, and embedded findings into the national dementia workforce development programme, Dementia Champions, recognised as one of the **UK's 100 best breakthroughs by MadeAtUni** for its significant impact on people's everyday lives. To date, we have graduated 1,000 Dementia Champions, preparing them to lead practice-based changes throughout the NHS in Scotland. In 2020, UWS was awarded an Advanced HE Collaborative Award for Teaching Excellence (CATE) 2020 for its groundbreaking Class in a Bag programme. Class in a Bag is a portable intergenerational education resource used by student nurses to teach school children about dementia and how they can help support people living with the condition drawing upon our research. More than 10,000 school children have learned from over 2,400 nursing students about dementia and have pledged to be dementia positive citizens. The Institute for Postgraduate Medical Education, Charles University Czech Republic [5.8b], used our Palliare BPS as a tool to map curricula and refresh educational programmes. Similarly, Spanish Universities of Alicante and Malaga [5.9], University of Porto, University Autonoma de Tamaulipas (Mexico) and University La Sabana (Columbia) [5.6] have created new modules on their health and social care programmes, inspired and informed by our research.

INFORMING POLICY: Our research-based, original definition of advanced dementia, delineation of best practice and illumination of care experiences have been used to challenge the Scottish Government to accept that all care needs arising from advanced dementia should be seen as healthcare needs, rather than through a social care lens. This has stimulated and informed political and public debate, through the auspices of the McLeish Commission, which based their analysis of inequalities around our definition of advanced dementia and description of best practice. The resulting major Alzheimer Scotland-instigated campaign, Fair Dementia Care Report (2019), has for the first time estimated the cost and quantified the scale of unmet need associated with advanced dementia care in Scotland. More than 15,000 members of the public have pledged support for the campaign's recommendations [5.10a] which have been debated by the Scottish Parliament:

"...the Parliament ... believes this to be an important contribution to the understanding of advanced dementia and the care needed by people across Scotland... we see a gaping hole in Scotland's policies." (Scottish Parliament 4th June 2019) [5.10b].

"..... The Parliament ... applauds ... the University of the West of Scotland for ensuring that the voice of lived experience sets the agenda for the next 10 years." (Scottish Parliament 9th October 2019). [5.10c].

5. Sources to corroborate the impact

5.1 Testimonial Alzheimer's Society Feb 2020

5.2 Evidence From Scottish Trade Union Congress:

- a) STUC Dementia in the Workplace: A Guide for Trade Union Reps, 2016.
- b) STUC Dementia in the Workplace training course evaluation and feedback, 2019.

5.3 Testimonial from Age Scotland, Feb 2020

5.4 Football/Baseball Reminiscence evidence

- a) *Improving the Lives ..using memories of baseball.* <https://tinyurl.com/1o85a737>
- b) Wingbermuehle et al (2014) *JAMDA* 15 (2) 85-89, DOI 10.1016/j.jamda.2013.11.006

5.5 Testimonial Together We Change the World Foundation, Poland.

5.6 Testimonial letter from University of Porto. December 2019.

5.7 Testimonial letter Erskine.

5.8 Evidence from Czech Republic:

- a) Testimonial Czech Alzheimer Society, November 2019.
- b) Testimonial Institute for Postgraduate Medical Education, Prague, Charles University
- c) Testimonial Centre of Gerontology. November 2019.

5.9 Evidence from Spain Testimonial University of Alicante. December 2019

5.10 Fair Dementia Care Campaign Evidence:

- a) Testimonial Alzheimer Scotland, November 2020
- b) Scottish Parliament meeting 4th June 2019 <https://tinyurl.com/3rfo5pgh>
- c) Scottish Parliament meeting 9th October 2019 <https://tinyurl.com/12h7lfvb>