

# Alzheimer Scotland Centre for Policy and Practice

Annabelle Gray  
Celebration  
Lecture 2019  
and Centre  
Report





## World's first Alzheimer tartan

Our signature Alzheimer Scotland – Action on Dementia tartan is the world's first tartan in recognition of the millions of people across the globe affected by dementia.

**Available from [www.alzscot.org/tartan](http://www.alzscot.org/tartan)**

Dementia Scotland Limited (Registered company no. SC296817) is a trading subsidiary of Alzheimer Scotland – Action on Dementia (Registered charity no. SC022315) to which it donates all of its profits. Dementia Scotland Limited – Registered office: 160 Dundee Street, Edinburgh, EH11 1DQ.

## Our collaborators





At UWS we are committed to providing world-leading dementia education in partnership with Alzheimer Scotland. Universities can make a huge difference to people’s lives, and I am thrilled that our education and research is having a transformative impact on the lives of people living with dementia.

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We are honoured to lead the national Scottish workforce development programme, and it is staggering to realise that by the end of this year we will have prepared 1,000 Dementia Champions. Every Dementia Champion takes with them into practice new evidence informed insights and change leadership confidence, so that they can make small and big differences to dementia care and people’s lives across Scotland.

Our dementia education track record includes an innovative spiral curricula that ensures future nurses completing our pre-registration programmes are knowledgeable and have the skills they need to practice at either the skilled or enhanced level of practice. Being able to practice at an enhanced level as a new mental health nurse registrant is just one of the UWS advantages.

This year’s Celebration Report applauds the inspiring contribution of a family carer to nurse education. We recognise and value the importance of family caring. It is no coincidence that the Carer’s Academy, piloted and continuing at UWS, won the Best Dementia Education Initiative at Scotland’s Dementia Awards 2019.

We are extremely proud of the impact our partnership with Alzheimer Scotland is having on not only those living with dementia, but their carers, families, and local communities. I am also proud of everyone involved in our dementia studies, including those working in the Carer’s Academy, our Dementia Champions, and of course our UWS nursing students. The reach of our dementia studies is fantastic and I look forward to seeing the rewards of new collaborations within Scotland, Europe, Canada and India. Dementia is a global challenge and our UWS staff and students are continuing to respond to this worldwide public health imperative.

“I am also proud of everyone involved in our dementia studies, including those working in the Carer’s Academy, our Dementia Champions, and of course our UWS nursing students.”

Professor Craig Mahoney,  
Principal and Vice-Chancellor, University of the  
West of Scotland



# 2019 in numbers



**6** Journal articles published

**8** Book chapters

**1** Edited book



**3** Award nominations



**1** Award win



**14** Grants received

**5** Countries visited  
Canada, India, Poland, Ireland, Netherlands.



**19** Conference presentations

**1** National campaign



<https://madeatuni.org.uk/>



**100** Dementia Champions trained

**30** MSc students

**250** CPD course attendees

**3** New PhD students



**6** Blog posts

**1** Goat



# Director's welcome



It has been another exciting and busy year for the Centre team and students.

Thanks to 34 contributing authors (staff, doctoral students and practice associates) we have published our first ASCPP textbook. The Textbook of Dementia Care: An Integrated Approach was edited by Professors Jackson and Tolson. This book, launched in May, will be a core text for our MSc Gerontology with Dementia students and a must read for pre-registration nursing and integrated practice students, Dementia Champions and Dementia Specialist Improvement Leads (DSILs).

Our post qualifying dementia education continues to support better care of people with dementia through the Dementia Champions (Scottish Government Workforce Development) Programme, DSILs, and bespoke dementia CPD. To date 900 Dementia Champions have completed the programme and with Cohort 10 underway this figure will soon reach 1,000. We have been part of the journey of over 100 mental health practitioners who have completed the DSLs Programme with our focus on Care Empathia.

We launched our Seasonal Seminar Programme with the help of Dr Shelley Peacock, who was our inaugural guest speaker for the Spring Seminar. We were so impressed with her work we moved quickly to invite her back to deliver this year's Annual Celebration Lecture, which you can read about later in this report.

Work with family carers features in this year's Celebration Lecture and the inspiring contribution of one of the many family carers who connect with UWS is being honoured. In partnership with NHS Ayrshire and Arran and the UWS academic team at the Ayr Campus, a Carer's Academy for people supporting relatives with dementia has been piloted. The Carer's Academy Model is an important innovation and as we go forward with this development we look forward to working closely with NDCAN members. You will find more

detail about the Carer's Academy and the leading team as you turn the report pages. We are also at the beginning of an initiative to support NDCAN research – but I will tell you more about that next year!

It has been wonderful to welcome many new faces to the Centre at Lanarkshire Campus not least Maple. You may have seen her on twitter #findingmaple, she is a care goat – yes really. Maple and Uno (dementia dog) stole the show at the May, UWS-Multi-Species Caring Workshop funded by the British Society of Gerontology.

Growing our international reach and networks has featured this year. Two standout achievements have been the success of family carer research collaborations with the University of Saskatchewan in Canada, and productive advanced dementia care collaborations and projects with Manipal Academy of Higher Education in India.

On a personal note, it has been a privilege to serve as a member of the McLeish Commission. If you have not yet signed up to support the Alzheimer Scotland Fair Dementia Care campaign to call for an end to advanced dementia care inequalities please follow our lead at [www.alzscot.org/fairdementiacarecampaign](http://www.alzscot.org/fairdementiacarecampaign). On pages 40-41 of the report you will discover how our ASCPP Palliare research has informed this call to action.

Finally, I would like to thank everyone who has supported us and for your interest in the work of the Alzheimer Scotland Centre for Policy and Practice at UWS.

## Professor Debbie Tolson

PhD MSc BSc (Hons) RGN FRCN PFHEA  
School of Health & Life Sciences  
Alzheimer Scotland Professor of Dementia  
Director of the Alzheimer Scotland Centre for Policy and Practice



# About the Centre

The Alzheimer Centre Scotland for Policy and Practice (ASCPP) is a collaborative partnership between University of the West of Scotland and Alzheimer Scotland. The Centre team is dedicated to excellence through education and research based scholarship and partnerships in practice. As a team we are proud of our achievements and the contribution we are making to improve the lives of people affected by dementia.

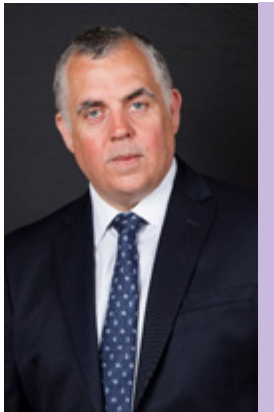
The Centre is based at the University's award winning Lanarkshire Campus; winner of the 2019 Guardian University Award for 'Sustainable buildings that inspire'. Our students also benefit from the award winning DOMUS facility, a simulated domestic environment where we explore low and high tech aids for living and care, and experience design that both helps and hinders care in the family home. Adjacent to the DOMUS are the Acorn Primary Care Unit, hospital simulation units and the Living Lab.





# Endorsements

## Chief Executive, Alzheimer Scotland



This has been another remarkable year for the Alzheimer Scotland Centre for Policy and Practice. Our shared aspiration of translating evidence-based research into meaningful policy and practice has again been strongly delivered.

The Centre played a key role in providing the research and practice evidence base for our Fair Dementia Care Commission and the subsequent Fair Dementia Care Campaign. The knowledge, understanding and expertise of the team at the Centre was a vital component in ensuring that the report conclusions and recommendations were as well informed and powerful as they could be. The work of the Commission highlights one of the greatest inequalities within our health and social care system; that

people with advanced dementia are consistently denied access to the health care they need and have to unfairly pay for their care. We are determined to use this expertise and knowledge to drive forward our campaign and bring an end to this injustice for people with advanced dementia. This exemplifies the interplay between research, policy and practice that we hoped would be achieved when we embarked upon this partnership.

The impressive breadth of innovation, research and practice work the Centre continues to lead on is quite remarkable, from wonderful innovations such as the Class in a Bag, to improving our understanding of dementia in the workplace and by providing such an immersive experiential opportunity through the DOMUS centre for so many students and professionals. As always, a highlight of the year has been the Dementia Champions Programme. We are fast approaching 1000 graduates, all of whom will have made such a huge impact within their local environment, continuously seeking to improve, adapt and change their practice. The success of this programme is clearly demonstrated by the number of Dementia Champions whose work has been showcased each year at Scotland's National Dementia Awards.

It is clear that the dedication and motivation of all the team to make such a huge difference is the true driving force behind the success of the Centre and on behalf of everyone at Alzheimer Scotland I want to say how grateful we are to the team for this and to thank you and the University for your ongoing commitment and dedication to improving the lives of people living with dementia and their families.

**Henry Simmons**



## National Dementia Carers Action Network (NDCAN)

NDCAN welcomes any opportunity to support Alzheimer Scotland Centre for Policy and Practice at University of the West of Scotland. The Dementia Champions programme has provided a high standard of much needed dementia specific training for health and social care professionals across Scotland, and the contribution of Carers from NDCAN has always been positively received. It is also a rewarding experience for the carers who are involved, knowing that our lived experiences can change perceptions, but also boost confidence for those already delivering good practice in their own workplaces. We will always welcome any opportunity to share experiences and engage in meaningful dialogue with professionals.

NDCAN members have also recently embarked on a new research project into Advanced Dementia with Professor Debbie Tolson and Dr Margaret Brown. Discussions are still in early stages, but we have identified three key areas of concern and interest – Communication, Keeping Safe and the Advanced Dementia Experience – all of which affect those living with dementia and their carers. We hope to finalise our first project topic very soon.

NDCAN look forward to continuing to support the team at UWS in the future.



## The Scottish Dementia Working Group (SDWG)

Once again, the Scottish Dementia Working Group (SDWG) has been fortunate to have had the opportunity to be part of the Dementia Champions Programme. SDWG members have shared their lived experiences of having dementia with the new cohorts of Dementia Champions, and as always, the Champions were very welcoming and passionate about hearing from them.

The SDWG value the Dementia Champions Programme greatly and believe that it is a vital tool in educating healthcare staff in how to support people with dementia whilst they are in hospital. This is important as each person with dementia is unique, and dementia is a different experience for everyone.

# Meet the team



**Professor Debbie Tolson**, DIRECTOR

Debbie is the Alzheimer Scotland Professor of Dementia and is an internationally recognised nurse leader, educator and researcher.

She has a particular interest in applied research that deepens understanding about advanced dementia and innovations in care that support the individual and enable family caring.



**Dr Margaret Brown**, DEPUTE DIRECTOR

Margaret is a Senior Lecturer and has considerable experience as a nurse, lecturer and researcher in dementia care. Her current interests include people with advanced dementia, their families and caregivers and the fundamental aspects of care. In 2016 she was awarded a Lifetime Achievement award for her contribution to dementia care.



**Dr Louise Ritchie**, LECTURER

Louise is a lecturer with a research focus within the Centre. Her research interests include dementia in the workplace, housing and psychosocial interventions for people living with dementia. She is currently leading the Dementia Inclusive Choir Network Evaluation and research activity on dementia in the workplace within the Centre.



**Dr Rhoda MacRae**, LECTURER

Rhoda leads on enterprise activities within the Centre. Her interests include advanced dementia, dementia in secure communities, loss and bereavement and knowledge translation. Rhoda teaches on the Dementia Champions programme, the MSc Gerontology with Dementia Care and MSc Leading People-centred Integrated Care and supervises a number of postgraduate students.



**Dr Anna Jack-Waugh**, LECTURER

Anna leads on educational focussed activities in the team including Scotland's National Dementia Champions programme. Her academic interest is research into the quality of educational strategies to support change and development of care practices when working in partnership with people with Dementia. Anna teaches into the undergraduate nursing programmes, the MSc in Gerontology with Dementia care and the BA (Hons) Integrated Health and Social Care programme.



**Raymond Duffy**, LECTURER

Raymond is currently the Programme Leader for MSc Gerontology with Dementia Care at University of the West of Scotland. He has been an educator and practitioner in older people's care throughout his career. He has a particular interest in long-term (chronic) illnesses and how these can affect people's experiences of living with dementia. He also has an interest in the role families and friends play in providing care and has been involved in educating and supporting carers since he became a health care professional. He also works with the team on delivering the National Dementia Champions programme.



**Susan Holland**, ALZHEIMER SCOTLAND DEMENTIA NURSE CONSULTANT (ASDNC), NHS AYRSHIRE AND ARRAN

As part of her ASDNC role, Susan has a defined teaching and research remit with the Alzheimer Scotland Centre for Policy and Practice. She has particular interests in dementia care within general hospital settings and post diagnostic support. Susan teaches on the Dementia Champions programme and works in collaboration with the ASCPP to strengthen links between research, policy and practice.



**Jenny Henderson**, ASSOCIATE LECTURER

Jenny is an Associate Lecturer and is a team member of the National Dementia Champions programme. Her main areas of interest are the care of people with advanced dementia and managing their palliative and end of life needs. She is also an advocate for the human rights and legal framework supporting people who lack capacity.



**Dr Graham Jackson**, EMERITUS PROFESSOR

Graham recently retired from his role as Professor in the Centre and was appointed Emeritus Professor. He continues his involvement in research related to people with dementia in prison populations and supervision of PhD students. He is also Clinical Advisor on Dementia to the Scottish Government.



**Professor Iva Holmerová**, VISITING PROFESSOR

Iva is an Associate Professor and CEO of the Centre for Gerontology, Praha 8. She is also the Chairperson of Alzheimer Europe. Iva is our visiting Professor at the Centre and a partner in the Erasmus+ Palliare Project.



**Carol Beckwith**, RESEARCH ASSISTANT

Carol Beckwith is a Research Assistant working on The Dementia Inclusive Choir Evaluation. Having gained an MA in Songwriting and a BSc in Psychology her interests are on the impact participation in creative activity can have on wellbeing. She took part in the 'Grace Notes' project in 2016/17 and will be taking part again in 2019 and is currently working on a project exploring 'Stories and Songs' with Dementia Carers in Glasgow.



**Dr Liz Carlin**, RESEARCH ASSISTANT

Liz is a lecturer in Sport and Exercise Psychology at UWS and teaching associate at Ulster University. Liz is currently working on a project looking at the social impact of a Dementia Friendly Walking Football Project based at Hampden Park and also has a research background in the social benefits of exercise for people with intellectual disabilities.



# Our Associates

- Dr Barbara Sharp, Policy and Practice Consultant, Alzheimer Scotland
- Henry Simmons, Chief Executive, Alzheimer Scotland
- Hugh Masters, Policy Consultant, Alzheimer Scotland
- Jim Pearson, Director of Policy and Research, Alzheimer Scotland
- Joyce Gray, Deputy Director Development, Alzheimer Scotland
- Gillian Anderson, Digital Lead, Alzheimer Scotland
- Charlotte Swarbrick, Digital Lead, Alzheimer Scotland
- Elaine Hunter, National Allied Health Professionals Consultant, Alzheimer Scotland
- Alison McKean, Allied Health Professions Post Diagnostic Lead, Alzheimer Scotland
- Jan Beattie, Deputy Director of Workforce, Alzheimer Scotland
- Susan Rendell, Dementia Learning Agent, Alzheimer Scotland
- Lindsay Kinnaird, Research Manager, Alzheimer Scotland
- Amy Dalrymple, Head of Policy, Alzheimer Scotland
- Kirsty Stewart, Head of Communications and Events, Alzheimer Scotland
- Dr Bryan Mitchell, Lecturer, University of the West of Scotland
- Julie Garton, Alzheimer Scotland Dementia Nurse Consultant, NHS Dumfries and Galloway
- Dr Shelley Peacock, Associate Professor, University of Saskatchewan
- Alison Toner, Lecturer, University of the West of Scotland
- Margaret Callaghan, PhD Student, University of the West of Scotland
- Angela Gregory, PhD Student, University of the West of Scotland
- Sam Quinn, PhD Student, University of the West of Scotland
- Dr Stuart Wood MBE, Independent Health and Music Researcher
- Dr Nick Jenkins, Senior Lecturer, University of the West of Scotland





# About the Annual Celebration Lecture

The Annual Celebration Lecture honours an outstanding contribution of a person or persons to our work. The University Celebration Medal is awarded to recognise those who have inspired us in our scholarship, our studies or in some way that has made a demonstrable impact on the way we, and others, respond to dementia.

## Annabelle Gray



The Alzheimer Scotland Centre for Policy and Practice are delighted to award the 2019 Celebration Medal to Mrs Annabelle Gray, wife of the late Bill Gray.

“Her positivity and ongoing dedication to improving dementia care is unwavering and her support over the years has been invaluable”

Annabelle and Bill set up home together in 1997 and were together for twenty one years. Bill was diagnosed with Alzheimer's disease in 2003, six weeks before he and Annabelle married, and he sadly died on 16th April 2018. Annabelle remained by Bill's side throughout their married life and even when Bill's care needs could no longer be met at home and admission to specialist dementia care was required, Annabelle adopted a "home to hospital" approach. The approach challenged many of the traditional boundaries of in-patient hospital care as it was based around a model of flexible day and night hospital visiting, the maintenance of homelife routines and activities and the active involvement of family as equal partners in care. However, the "home to hospital" approach enabled Annabelle and Bill to remain connected throughout his time living with dementia, positive staff/family relationships to be developed and person/family centred approaches to care to be established.

Annabelle also works alongside Susan Holland, Alzheimer Scotland Dementia Nurse Consultant, NHS Ayrshire and Arran; Alison Toner, Lecturer in Mental Health Nursing, University of the West of Scotland and the wider mental health lecturing team at UWS to help shape the education of mental health and adult nursing students and inspire their interest in dementia care.

In 2013, she started to come into university to share, with the Year 3 mental health student nurses, the journey she and Bill experienced leading up to his dementia diagnosis and the story of their life together. To come and speak with a class of future mental health nurses was initially daunting,

however the grace and eloquence in which Annabelle presents her narrative is to be commended. The opportunity to hear Annabelle share the love story of her and Bill is truly a privilege and using personal photographs and personal narratives, she enables student nurses to gain an insight and understanding of the carer's role.

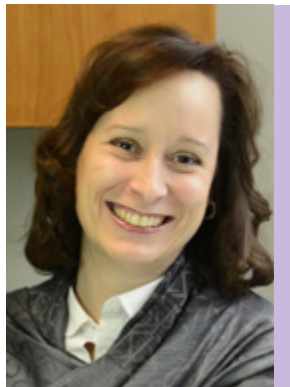
Annabelle continues to only too willingly give up her time to input to the pre-registration nurse education programme. By sharing her and Bill's life story she has helped to educate, inspire and instil a deeper sense of empathy, compassion and shared understanding of the needs of both the person with dementia and their loved ones. Annabelle remains a strong advocate for ensuring that families and carers are pivotal to the decision-making process and she continues to represent the voice of family carers on the UWS Curriculum Development Steering Committee for the new pre-registration curriculum development.

Her positivity and ongoing dedication to improving dementia care is unwavering and her support over the years has been invaluable. She has challenged and inspired our students to find creative ways to support family caring. We are in no doubt that the impact of her voice and this special love story will stay with them throughout their nursing careers.



# The speaker

## Dr Shelley Peacock



Dr. Shelley Peacock is an Associate Professor with the College of Nursing at the University of Saskatchewan in Saskatoon, Canada and a registered nurse with 20 years of experience in

practice with persons living with dementia and research of supporting family carers to persons living and dying with dementia.

Shelley teaches undergraduate courses in foundational nursing care and assessment skills and teaches research methods in the graduate program in the College of Nursing. Shelley has the privilege of supervising and supporting several graduate students in nursing and psychology at the University of Saskatchewan. She has been recognised for her teaching with the University of Saskatchewan Students' Union Excellence in Teaching Award in 2016, as well as receiving the Saskatchewan Registered Nurses Association's Nora Armstrong Award for Excellence in Mentorship in 2018.

Shelley's program of research focuses on optimising the well-being of family carers and persons living and dying with dementia. Her research is funded at the provincial and national levels and includes working with colleagues from across Canada and Scotland. Her work has involved developing a writing intervention for older adults bereaved of a spouse with dementia, known as the Reclaiming Yourself Tool. Funding from the Saskatchewan Health Research Foundation, in partnership with the Centre for Aging and Brain Health Innovation,

supports Shelley and her colleagues in developing the RuralCARES app to support family carers of persons with rare-dementias in rural Saskatchewan. Other current research collaborations include evaluating the sustainability of the My Tools for Care – In Care web-based intervention for use across Canada (funded by the Public Health Agency of Canada) and a project to develop music boxes as a means to improve the relationship of couples living with dementia (funded by the Saskatchewan Health Research Foundation in partnership with the Centre for Aging and Brain Health Innovation). Shelley's latest international work with Scottish colleagues is funded by the Canadian Institutes of Health Research and is aimed at adapting the Dementia Champions Programme for use in Canada.

Shelley has widely published her research. She is the author of several systematic literature reviews in the context of dementia with respect to: effectiveness of interventions for family carers, correctional settings, use of light therapy for managing distressed behaviours, and the state of end-of-life care. Other publications are of her varied research projects, including experiences of family carers and older adults living with dementia and multiple chronic conditions; acceptability and availability of health care services for persons with dementia living in the community; and earlier work related to the web-based intervention, My Tools for Care. Most recently she co-edited the book, *Hospice Palliative Home Care and Bereavement Support: Nursing Interventions and Supportive Care* (2019) with her colleagues Drs. Lorraine Holtslander and Jill Bally.

“When we consider what living with dementia encompasses stories can act as gifts.”

## LECTURE ABSTRACT

### THE 2019 ANNABELLE GRAY CELEBRATION LECTURE THE POWER OF STORIES

In one way or another, we are all a part of stories. Stories hold power. Stories call us to contemplate, to challenge, to identify, to teach, to inspire, whether we are the story-teller or the one hearing the story of another. This lecture will focus on the power of spoken stories shared by carers and persons living with dementia. Story-telling encompasses three elements: the subject, the story-teller, and the listener.

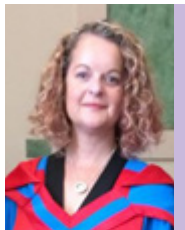
When we consider what living with dementia encompasses, stories can act as gifts. It is through the sharing of stories that we come to know and appreciate another in profound and meaningful ways – whether it is a carer or a person living with dementia. Carers who are able to share the story of their caregiving journey enlighten us to the realities of dementia. Stories may also give voice to a person who has been changed by their dementia and allow us to understand who they were before their dementia and who they are becoming as someone living with dementia.

The receiver of stories may be friends, students, or others just starting on a journey with dementia; by hearing stories each of these groups are afforded a window into dementia that no textbook, pamphlet, or website can provide. Stories give flesh to the complicated life circumstance of dementia. As the listeners, we have an awesome responsibility to respect and appreciate the story. When we stop and truly listen to what a carer or person living with dementia is sharing, we have the opportunity to honour their story, provide them the therapeutic expression of their lived experience, and perhaps begin to understand how best to support them.

This lecture is meant to honour carers like Annabelle Gray. Annabelle's sharing of her and Bill's incredible story has benefited countless students and other carers. Annabelle's story has functioned as a way to reduce stigma and challenge the barriers to living with dignity that dementia may impose. That is the power of stories.



# Student successes



## Dr Anna Jack-Waugh

Congratulations to Dr Anna Jack-Waugh who this year has completed her five-year doctorate at Glasgow Caledonian University. Anna's study used a theory-methods approach to construct a theory of the learning experienced by Scotland's National Dementia Champions (health and social care professionals). Twenty-one Dementia Champions engaged in concurrent data generation and analysis. The findings are a storyline of the learning experiences of the Dementia Champions.

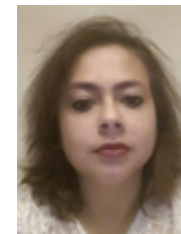
The Champions explained that in their past, they had been educated, socialised and defined for failure; their theory classes contained minimal content to prepare them to work with people with dementia; then they went to placements where the care they observed for people with dementia lacked humanity. As young people in their profession, they vowed never to work in those settings again. Their hospitals and colleagues told them there was no place for people with dementia in their areas; ultimately, people with dementia were rejected by the people who were supposed to help them. The Champions then reported they encountered an increase in people with dementia coming into their areas they felt unprepared for.

On the programme, multiple learning activities in which interacting with the experience of people with dementia, their families and colleagues became the stimulators of change. Each Champion had unique interpretations and individual meaning-making on the programme; which lead to a shared outcome of pride and a feeling of competence when working with people living with dementia.

The change the Champions experienced was one of self-definition and definition of people with dementia. The process of change was painful; during the programme, the Dementia Champions understood how they defined themselves as proud, competent professionals were erroneous. They reflected and experienced pain when they thought about what they had done in the past to people living with dementia. They found their professional identity a barrier to change, so profoundly had they been socialised to reject people living with dementia.

The findings are significant because they illuminate the negative long-term impact of knowledge and skills gaps in professional programmes. It also illustrates how the current structures of hospitals and services may become so specialised that they reject those they define as not their patients.

The findings of Anna's research showed a continued need for dementia-focussed education in all areas of health and social care and research into that education to make up for the generations where dementia knowledge and skill development was absent.



## Debjani Gangopadhyay

Debjani has successfully completed her MPhil with the Centre and is due to graduate in 2019. Supervised by Professor Debbie Tolson, Dr Louise Ritchie and Dr Beverley Young with support from Professor Graham Jackson, Debjani's MPhil research developed an educational intervention for care assistants working in care homes to promote appropriate use of non-pharmacological interventions and reduce the use of psychotropic medication for people with dementia. As part of the intervention she developed the UReACT tool which could be used as an initial method of management of stress and distress in residents by the healthcare assistants. UReACT stands for Understanding the Resident with dementia and stress and distress; Assessing the resident; Communicating with the resident and managing and addressing Triggers which are responsible for the development of stress and distress. The development of the tool was based on behaviourist learning theory and Theory of Planned Behaviour and results showed a positive change in attitude of hope towards dementia among the participants. It is expected that if UReACT is used repetitively by staff it could have the potential to improve attitudes towards dementia and eventually reduce the use of psychotropic medication when people with dementia are experiencing stress and distress. However more rigorous research in future would be able to determine the effectiveness of this intervention.

Debjani is currently working as a research intern in the ASCPP carrying out a literature review exploring dementia care experiences and challenges faced by caregivers, family members and local community in South East Asia



## Jane Mimnaugh, MSc student

Jane is a Senior Charge Nurse in Ward 3, University Hospital Wishaw (a 23 bed functional mental health acute admission ward for older adults). As a Registered Mental Health Nurse with an interest in older adults and dementia, Jane has this year completed her MSc in Gerontology with us. Following an incident in her ward, and having attended an interesting lecturer at UWS from a staff member from Shotts prison, Jane decided to focus her studies on marginalised groups. She decided to compare and contrast two marginalised populations, people living in care homes and prison for her Contemporary Issues in Ageing module. This then sparked an interest which followed into her dissertation year to look at the care and treatment of older prisoners who develop dementia. Jane produced a first class dissertation and is hoping to publish her work following graduation in November. Jane has been an outstanding student throughout her programme and this has been recognised with the award of the Court Medal for the MSc Gerontology programme. Jane is a great example to our other students, and our team are proud to have helped Jane develop and achieve throughout her programme. We know that Jane will go on to use the knowledge from her MSc to make a difference to the lives of people living with dementia.



## Meet our new PhD student



### Angela Gregory, PhD student

Angela Gregory joined the Centre as a PhD student at University of the West of Scotland in August 2019. With a background as a Freelance Artist, and more recently as an Occupational Therapist, Angela will spend the next three years working on a PhD jointly funded by Alzheimer Scotland and Erskine Care. As an occupational therapist, Angela is interested in understanding how we can work collaboratively with people with dementia, families, and care home staff to enable people to maintain as much independence as possible and engage in meaningful activity. Angela's research will support human rights and improve quality of life for people with advanced dementia living in a care home through engagement in meaningful activities. People with advanced dementia have fewer opportunities to engage in activity attuned to their reduced communication, understanding and mobility. This leads to reduction in movement, fewer opportunities to experience pleasure, limited social engagement and more rapid deterioration. Working directly with people at the advanced stage of dementia, this study will examine equal opportunities for activity and find new ways and ideas to increase quality of life. We are delighted to welcome Angela to the team and look forward to hearing how her research progresses.

## Research spotlights

### SCOTLAND'S NATIONAL DEMENTIA CHAMPIONS



This year cohort 9 of Scotland's Dementia Champions programme graduated in March at Murrayfield Stadium. One month later, over a hundred health and social care participants walked through the doors of the new University of the West of Scotland Lanarkshire Campus to commence cohort 10.

The breadth and depth of Scotland's National Dementia Champions programme are difficult to capture fully as the work of the Dementia Champions is spread across the majority of Scotland's health and social care areas. We launched #oneweething on twitter in 2017 to encourage Champions to share the changes they have made to their practice area. A glance at the #oneweething reveals:

- Dementia Champions in Podiatry celebrating their year of working together
- Specialist orthoptists demonstrating how they have used their action plan to improve the care of people with dementia in their department

- NHS Fife Dementia Champions presenting their work on using music to support people living with dementia in hospitals
- Physiotherapists in Edinburgh increasing the department's dementia awareness
- Senior charge nurses targeting reducing patient falls
- Experienced nurse champions from Edinburgh having the courage to return cohort 10 to inspire the new Dementia Champions exiting their cohort
- Scotland's Dementia Champions participating in Dementia Awareness Week across the country

Additionally, the Dementia Champions continue to contribute to research with the aim of understanding the need for dementia education improvements. In conjunction with colleagues at the University of Dundee the education team are refining a tool to measure the knowledge gained through dementia education. A recent article authored by the Higher Education Dementia Network (HEDN) which the Dementia Champions education team are part of, highlighted the role of professional bodies in guiding and influencing dementia education in all health and social care programs. There is a need to develop more sensitive ways of capturing the impact of dementia education both qualitatively and quantitatively.

## DEMENTIA INCLUSIVE CHOIR NETWORK

Life Changes Trust, in collaboration with the Baring Foundation have recently commissioned Luminate Scotland to develop and administer a Dementia Inclusive Choir Network (DICN) for Scotland. The Network aims to connect the existing choirs in Scotland, promote and support the creation of new choirs and work as an advocate for the promotion of arts-based activities and interventions to support and enable those affected by dementia. In April 2019, Dr Louise Ritchie and Dr Margaret Brown were commissioned by Life Changes Trust to evaluate the DICN and to carry out research exploring the impact of choral singing for people with dementia. Working with Dr Stuart Wood OBE, an Independent Music and Health Researcher and Carol Beckwith, a musician and researcher the project aims to:

- Understand the impact singing in choirs has on people with dementia and their family carers
- Assess the working of the Dementia Inclusive Choir Network in terms of its ability to raise awareness of dementia and improve access to the arts for people affected by dementia within Scotland

The research will use innovative video technology to capture the 'in the moment' experience of choir participation, and reflective interviews with participants will provide a rich description of the choir experience and the impact this has on people living with dementia. This will be complemented by the use of the Music Matrix tool, developed by Dr Stuart Wood and colleagues which is an observation tool to measure the outcomes of music activities. This will help us to explore the extent to which choirs are inclusive of people with dementia and develop an understanding of how choirs can become dementia inclusive. This project will run for two years, so look out for an update with the initial findings in 2020!

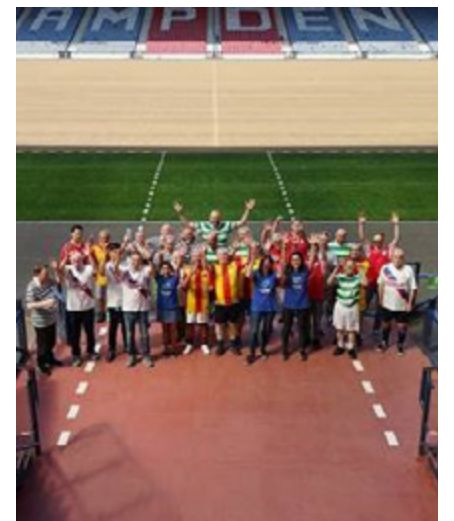


## PILOT DEMENTIA-FRIENDLY WALKING FOOTBALL PROGRAMME

Dr Eilidh Macrae and Dr Rhoda Macrae have secured funding from the R S MacDonald Trust to evaluate the social impact of a pilot, monthly Dementia Friendly Walking Football programme on the lives of men living with dementia and the people who care for them. Chris Kelly, Volunteer Coordinator from Alzheimer Scotland is organising the programme. Sessions are led by Hampden Sports Clinic and have taken place on six occasions between April and September this year at Hampden Stadium.

At each session everyone gathers in Hampden Stadium café to socialise before the players go to the changing rooms to get ready. Following a physical warm up, short matches are played in the indoor pitch. Supporters cheer on during the very lively games with players trying to keep in the spirit of walking football and not running. After the games everyone goes out on to the Hampden pitch to enjoy the atmosphere and get their photos taken. Following lots of changing room banter, it is back to the café for a well-earned refreshment. Alzheimer Scotland staff and volunteers are there throughout for support and advice.

The evaluation is exploring participants' carers and supporters' experiences of this monthly dementia-friendly walking football programme. The research team are attending the sessions and aim to carry out in-depth semi-structured interviews at two time points with 10 participants, 10 carers and three volunteers or staff. We will explore perceptions of change in relation to health and wellbeing, mind-set, social experiences, social interactions, mood, energy levels and physical activity. The results will be reported in Spring 2020.





# Education and innovation

## THE TEXTBOOK OF DEMENTIA CARE: AN INTEGRATED APPROACH

Professors Debbie Tolson and Graham Jackson have edited and contributed to an evidence-based textbook, which gives an overview of the topic of dementia, with an emphasis on practice. Taking a collaborative approach, it is written by authors from a wide range of health and social care backgrounds and includes the perspectives of people with dementia, as well as family carers, with contributions from doctoral students from the UWS – Alzheimer Scotland Centre for Policy and Practice (ASCPP) and other staff from within the UWS School of Health & Life Sciences.

Designed for professionals undertaking further study in dementia care, this book will also support pre-registration students undertaking placements in the area and will prove to be an important resource in the workplace. The book makes an important and contemporary addition to resources available to practitioners and students in health, social and integrated care.

It will be the designated core text for UWS courses in this area and recommended reading for both the undergraduate and MSc programmes.

Additionally, the inter-professional approach adopted demonstrates the excellent networks which exist between the ASCPP and a range of stakeholders.

For more information and to buy this influential textbook, please visit <https://www.routledge.com/Textbook-of-Dementia-Care-An-Integrated-Approach-1st-Edition/Jackson-Tolson/p/book/9781138229235>



## CARE EMPATHIA: LEARNING THROUGH THE HEAD, THE HEART AND THE HAND



We are expanding our Care Empathia approach to learning about dementia, most recently with staff from NHS Ayrshire and Arran, supported by their Alzheimer Scotland Dementia Nurse Consultant, Susan Holland. The Care Empathia approach was developed by the team and uses cognitive, emotional and practical learning and teaching strategies to connect with older people and people affected by dementia.

This year we have piloted the approach with year one and two students in the pre-registration nursing programmes in Lanarkshire and Dumfries to prepare for the new nursing programmes in 2020.

Moving out of our comfort zone in health and social care, we are developing the approach with our colleagues in sports science. We have begun to use Care Empathia to support learning with sports science students and introduce them to the exercise potential of older people and people with dementia. Thank you to our colleague Dr Angela Beggan, their tutor, for recognising the potential for learning using this approach.

This year we presented our efforts at the Annual UWS Learning, Teaching & Research Conference in a seminar entitled 'Old age is not for sissies', with our sports science and nursing lecturers and student colleagues from both courses, nursing and sports science.

Following our successful summer school in the University of Alicante in 2018, we hosted an Erasmus student, Sara Pacheco. Sara had placements in a local specialist dementia unit and community mental health team, developing her knowledge and practice using the Care Empathia approach. At a meeting with Jamie Hepburn MSP, Minister for Business, Fair Work and Skills, she helped him understand the impression Scottish care approaches had made on her.

After four months here with us in Scotland, she presented her experiences to her fellow students and staff at the University of Alicante at their summer conference.



## MSc GERONTOLOGY WITH DEMENTIA CARE

The MSc in Gerontology with Dementia Care has been created in response to the demographic evolution and the difficulties faced by those living with dementia, their carers and their families. Now on its second year of delivery, the programme combines original research by Alzheimer Scotland Centre for Policy and Practice including the Palliare project and the pedagogical expertise honed on all the Centre's activities including Scotland's National Dementia Champions programme delivery.

The MSc aims to develop the knowledge, skills and confidence of all its participants by introducing debate around our understanding of ageing, the impact of shifting demographics and the integration and globalisation of health and social care with a particular focus on the care of people living with dementia, and their current and future care priorities.

We look forward to supporting the future actions of the current first and second years as they develop and apply their learning to lead Scotland's future in dementia research, policy and practice.

## CONTRIBUTION TO INTEGRATED PRACTICE

### Caring for Frail Older People: A Coaching and Educational Intervention for District Nurses and the Primary Care Team

Our Centre is involved in an innovative two-year project, funded by the Burdett Trust and led by Dr Constantina Papadopoulou. The project will help organisations to build capability to provide and sustain high-quality care and support for people in the community who are frail.

District Nurses hold a unique role in the community, with deep knowledge and understanding of the needs of people who are frail, and their family carers, engaging, influencing and mobilising other professionals and community assets to improve the experience of care and outcomes for people.

Employing a participatory action research approach, patient and family carers will be involved in person-centred coaching sessions. This knowledge combined with practical education for the whole team on effective interventions will be employed to generate valuable, transferable learning.

## BA (Hons) Integrated Health and Social Care and MSc Leading People-centred Integrated Care

At UWS we successfully developed the BA (Hons) Integrated Health and Social Care (and with Administration route) and MSc Leading People-centred Integrated Care. Both programmes have been built alongside the strong links with the International Centre for Integrated Care and the Alzheimer Scotland Centre for Policy and Practice. The ethos behind both is to enable and empower the students to deliver, develop and lead integrated services in order to promote and enhance quality, effective and efficient people-centred services.

A key feature of both programmes is that, through the multi-professional and multi-sectoral nature of shared co-productive learning to integrated care education, students can explore the complexities and challenges of delivering and leading system integration. This is advocated as a way of breaking down professional boundaries and in developing a more cohesive approach to professional practice. This allows shared and asset-based learning to take place between the diverse roles of the students and staff, in addition to the impact on the cultural appreciation and shifts that are required to ensure the delivery of transformative, integrated, person-centred services.

### For further information

BA (Hons) Integrated Health and Social Care please visit:  
<https://www.uws.ac.uk/study/undergraduate/undergraduate-course-search/integrated-health-social-care/>

MSc Leading People-centred Integrated Care please visit:  
<https://www.uws.ac.uk/study/postgraduate/postgraduate-course-search/leading-people-centred-integrated-care/>



# Local impact

## CARER'S ACADEMY

During 2018/2019, a six-month pilot "Carer's Academy" project was co-developed and co-led by Susan Holland, Alzheimer Scotland Dementia Nurse Consultant (ASDNC) and Alison Toner, Lecturer in Mental Health Nursing, with support from the Alzheimer Scotland Centre for Policy and Practice (ASCPP). The purpose of the Carer's Academy is to provide state-of-the-art practical skills-based learning and information that will support and sustain family caring of a relative with dementia.

The approach which has been piloted is based on a combination of situated and vicarious learning. This means that the methods of learning used are planned and delivered to reflect real life situations, and that the experience-based expertise of all is respected and valued. In this way we appreciate the dynamics of family caring and carer expertise therein, we value and welcome in the moment peer-to-peer learning that arises during carefully planned and managed learning experiences led by experienced ASCPP/UWS/ NHS team members and practice associates.

Evaluation results from the pilot project indicate that the programme produced positive changes on all three outcome measures:

- Enhanced knowledge and understanding of dementia
- Development of practical caring skills
- Peer-to-peer learning

All 43 of the family carers who attended the Carer's Academy reported enhanced levels of knowledge and skills following attendance. This resulted in increased levels of understanding and empathy towards loved ones living with dementia and increased levels of confidence regards the ability to implement strategies to support the maintenance of independence and to prevent/minimise stress and distress.

Practice in the delivery of the fundamentals of care also led to the development of renewed confidence, motivation and skill which enabled fundamental care activities which were previously felt to be too difficult to manage to be successfully re-initiated. Feedback also suggests that attendance at the Carer's Academy was helpful in supporting carers to reduce/manage areas of identified risk and to plan and prepare for future care needs. The opportunity to receive peer support was also invaluable in easing feelings of guilt, isolation and supporting self-expression and shared learning.

The value of the Carer's Academy project has been recognised nationally. It was the winner of Best Educational Initiative at Scotland's Dementia Awards 2019. This work has also contributed towards Susan Holland being nominated as "Leader of the Year" in Scotland's Health Awards 2019. A priority for the coming year will be to explore with NDCAN members how we build upon this initial work to expand and develop the Carer's Academy.

## BSG DEMENTIA AND MULTI-SPECIES CARING WORKSHOP

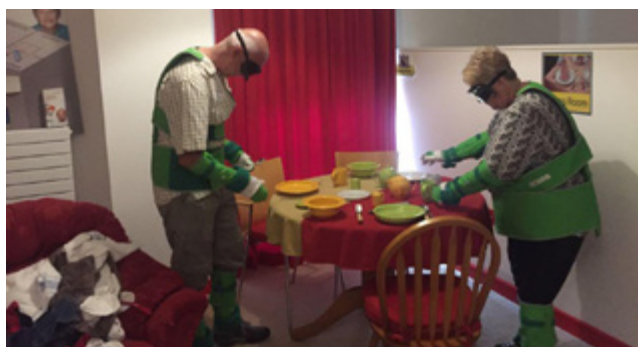
58 people attended the 'Dementia & Multi-Species Caring: Current Practice & Future Possibilities' workshop, on 28th May 2019 at University of the West of Scotland (UWS) Lanarkshire Campus. This workshop was funded by a grant awarded by the British Society of Gerontology to Dr Nick Jenkins, Dr Anna Jack-Waugh and Dr Louise Ritchie. Opened by Professor Debbie Tolson, participants came from a wide variety of backgrounds – including academic research, health and social care practice, funding, policy-making, animal welfare and lived expertise. Our programme of speakers was equally diverse and definitely 'multi-species'. Our speakers included:

- Fiona Corner, together with Henry and Anne Rankin, provided an overview of the Dementia Dog project.
- Dr Anna Jack-Waugh (UWS) – together with Julie Garton (NHS D&G), Mandy Cowan (Alzheimer Scotland) Alison Mann (Leaning with Horses) and Juanita Wilson (Mossburn Community Farm) – presented an emerging programme of psycho-social, education-based sessions currently being developed at Mossburn Community Farm.
- Heather Clements (UWS) presented from her doctoral research, exploring the impact of fish aquaria (and digital fish tanks) on health

and wellbeing across a range of settings, including residential care homes for older people.

- Mary Morris (Care Inspectorate) and Jim Melville (Campbell Snowdon House) followed Heather's presentation by co-presenting Animal Magic – a 2018 report from Scotland's Care Inspectorate that links explicitly, human-animal companionship to the Scottish Government's newly-developed National Care Standards.
- Lorena Sordo from Edinburgh University's Roslin Institute (the home of 'Dolly the Sheep') presented from her doctoral project, which explores Cognitive Dysfunction Syndrome (CDS) amongst elderly cats.

It would have been somewhat strange for an event like this not to include (non-human) animals in its proceedings. As such, supporting our speakers was a trained Dementia Dog (Uno); a tank of tropical fishes; a turtle (Tessa); and Maple the goat (yes... a goat). As you might imagine, completing the risk assessment for this workshop was not a task for the faint of heart and it was good to see a university that openly prides itself on 'daring to be different' being willing to host such a multi-species meeting within its walls.





## ALZHEIMER SCOTLAND AND ASCPP COLLABORATION DAY 2019

In March 2019, we held our first collaboration day for the partnership between the Alzheimer Scotland Centre for Policy and Practice (ASCPP) at University of the West of Scotland and Alzheimer Scotland (AS). Held at the new UWS Lanarkshire Campus, it was a great opportunity for colleagues to connect, explore and plan future possibilities for the partnership.

We used Ketso to produce a plan of action and you can see from the photos that we had an interesting and colourful workshop. Finished maps have 'branches' showing themes from the discussion.

We agreed some key possibilities

- Work more closely on research projects and funding opportunities.
- Develop opportunities for working together with joint appointments, secondments and co-location.
- Greater sharing of online presence and digital sharing of promotional material.
- Decide on shared priorities and make these defined and visible.
- Make our partnership synonymous with expert knowledge.



## ALZHEIMER SCOTLAND ANNUAL CONFERENCE 2019

At Alzheimer Scotland's Annual Conference as part of Dementia Awareness Week 2019 ASCPP staff and associates were involved in a number of activities, including poster presentations, chairing sessions, presenting, and publicising the work of the Centre. Below is a summary of some of the exciting activities we were involved in.

### Emergency Service Dementia Pledge

Scotland's emergency services joined forces to collectively sign a dementia pledge, to support people living with dementia and their families. Led by Dr Anna Jack-Waugh from the ASCPP, the Scottish Fire and Rescue Service, Police Scotland, the Scottish Ambulance Service and Alzheimer Scotland, came together in 2017 to form the 'Dementia and Emergency Services Collaborative'. As part of their work, the emergency services 2025 dementia pledge commits the emergency services to work towards improving the safety and wellbeing of people living with dementia, their families and carers who they come into contact with.

The 2025 dementia pledge commits the Dementia and Emergency Services Collaborative to:

- Ensure emergency services staff collectively have the knowledge, skills and understanding to recognise and support people living with dementia before, during and after an emergency incident.
- Work towards becoming dementia-friendly employers to help support colleagues who become carers or support those whom themselves develop dementia.
- Increase inter-professional working across the emergency services and beyond, to maintain and improve the general safety and wellbeing of people living with dementia, their families and carers.
- Support organisations and individuals across Scotland to develop more dementia-friendly communities.

The pledge has been brought together through collaboration with people living with dementia in consultation with the Scottish Dementia Working Group (SDWG).

### Complementary Therapy Workshop for Delegates

One of our Associates, and former PhD student, Dr Bryan Mitchell provided one to one taster sessions of Complementary Therapy at the Alzheimer Scotland conference during the 'Being Good to Yourself Workshop'. These sessions were provided alongside Karen Black, a community activities organiser at Inverness Services, who was additionally providing Thai hand massage. A current student on the BSc Professional Health Studies programme, Lisa Stirling, who also has a background in Complementary Therapy also assisted due to the anticipated volume of interest at this workshop. These interventions were provided on a voluntary basis to conference delegates where the main aim was to offer each individual the opportunity to experience what Complementary Therapy is and feels like. These sessions were well received at the conference where the workshop was fully booked throughout.

### Breakout Presentation

Professor Debbie Tolson and Dr Margaret Brown were involved in delivering a breakout session to delegates on the theme 'Care today: Forging ahead in acute care'. This session, which was chaired by Professor Tolson, discussed the variable experiences of people with dementia who use acute care services. Dr Margaret Brown, alongside Hugh Masters and Alzheimer Scotland Dementia Nurse Consultants Helen Skinner and Lyn Irvine participated on the panel which showcased the improvements that are being led by Dementia Nurse Consultants and Dementia Champions across Scotland. The panel explored what is working well and what still needs to be done to improve our general and community hospitals.



# International developments

## SUPPORTING CANADIAN FAMILY CAREGIVERS THROUGH EDUCATION FOR THE HEALTHCARE WORKFORCE



In March this year, Rhoda MacRae travelled to Edmonton, Canada to contribute to a two-day event focussing on the design of education following a series of Delphi rounds with fellow applicants, family caregivers, healthcare professionals, policy makers, educators and managers. Funded by the Canadian Institute of Health Research, Rhoda is a co-investigator on a grant led by Covenant Health (a large healthcare provider), the University of Calgary and the University of Alberta. This work builds on our growing collaboration in Canada and

Rhoda is currently working on a number of research projects and activities with colleagues in Canada, including this year's Celebration Event speaker, Dr Shelley Peacock.

Rhoda's work centres on sharing learning from the Scottish context, particularly from the Dementia Champions programme to inform dementia care education in Canada. As a result, the Canadian Institute for Health Research has funded a project to prepare a collaborative action plan with people with dementia and family carers, dementia organisations and six universities to adapt Scotland's National Dementia Champions Programme to the Canadian context. This project will undertake a number of activities to understand the current level of dementia education available for qualified healthcare professionals in acute hospital settings across Canada and use this to design an adapted dementia care education programme tailored for the Canadian acute care context. This will help to build multidisciplinary collaborations across Canada and with Scotland to facilitate the future implementation and evaluation of the adapted programme. Rhoda and Anna will talk about Scotland's National Dementia Champions programme at a two-day network planning meeting due to take place in Canada in February 2020.

Additionally, Rhoda is working with Professor Wendy Duggleby, Associate Dean of Research, Nursing Research Chair in Aging and Quality of Life, University of Alberta to adapt an online psychosocial intervention for caregivers that Wendy and colleagues have feasibility tested and is now operational in Alberta. Along with Alzheimer Scotland we are currently seeking funding to adapt the tool for caregivers in Scotland.

## CARERS RESEARCH: MENTAL WELLNESS APP FOR RURAL CAREGIVERS

This Canadian project led by Associate Professor Shelley Peacock, Faculty of Nursing, University of Saskatchewan is to adapt a caregiver co-designed mental wellness app for rural caregivers of persons with dementia: RuralCARES. Funded by a Collaborative Innovation Development Grant from the Saskatchewan Health Research Foundation, the app will support caregivers of people with atypical dementias, commonly young onset, living in remote and rural areas participate in Telehealth support groups. We hope the app will inform the way Alzheimer Societies offer support services to rural caregivers. It is part of a portfolio of work being undertaken by Rural Dementia Action Research Team (RaDAR) - [https://cchsa-ccssma.usask.ca/ruraldementiacare/news-articles/2019\\_RRMCI\\_Launch.php](https://cchsa-ccssma.usask.ca/ruraldementiacare/news-articles/2019_RRMCI_Launch.php)

## ANIMAL ASSISTED INTERVENTIONS FOR PEOPLE LIVING WITH DEMENTIA IN THE NETHERLANDS

IDr Anna Jack-Waugh, Julie Garton from NHS Dumfries & Galloway and Mandy Pool, Alzheimer Scotland travelled to the Netherlands in August 2019. Funded by the General Nursing Council and Alzheimer Scotland, the field trip was to explore animal-assisted interventions for people living with dementia. The team visited two Green Care Farms, met people living with dementia on the farms and researchers Simone De Bruin and Jan Hassink who lead the Green Care Farm research and practice in the Netherlands. The learning and observations from the trip will contribute to the animal-assisted care projects by the Alzheimer Scotland Centre for Policy and Practice team.





## ADVANCED DEMENTIA AND DEMENTIA RELATED HARDSHIPS IN SOUTHERN INDIA

Professor Debbie Tolson, Dr Louise Ritchie and Dr Anna Jack-Waugh were successful in securing a grant from the Scottish Funding Council Global Challenges Research Fund. Working with colleagues from Manipal Academy of Higher Education (MAHE) in Karnataka, India this research project aimed to explore the experience of people living with dementia and their family carers in India with a focus on understanding issues related to advanced dementia-related elder abandonment and abuse.

With some four million people diagnosed with dementia, there is an urgent need within India to develop dementia education aligned with the UN's Global Sustainable Development Goals. Advanced dementia within India is a hidden problem which places individuals, and their sometimes young carers, at high risk of poverty and other inequalities. There is an immediate need to develop practical and theoretical understanding among practitioners, policy decision-makers and the public about advanced dementia, alongside an understanding of advanced dementia-related abuse and abandonment.

The project involved a number of activities including a review of the literature, scoping of current services and community-based focus groups with key stakeholders to gain insight into experiences of care and advanced dementia related hardships.

Dr Anna Jack-Waugh and Dr Louise Ritchie spent 10 days visiting Manipal in April 2019. While there they were involved in data collection for the project and were keynote speakers at the IndoScotland Symposium on Advanced Dementia, along with Professor Tolson who due to a fractured ankle contributed via video. The symposium was attended by over 250 delegates, including students, academics and healthcare practitioners.

A Memorandum of Understanding between UWS and MAHE was signed at the event, and was commemorated by the presentation of a Scottish Quiach – 'the cup of friendship'. We look forward to developing dementia research and community dementia education collaborations with colleagues in Manipal over the coming years.





# Policy influence

## FAIR DEMENTIA CARE

The Fair Dementia Care Commission was established by Alzheimer Scotland in 2017 to review and make recommendations on how Scotland cares for people living with advanced dementia. This hard-hitting report reveals many inequalities facing individuals and families and makes a number of policy and system reforming recommendations. Not least, unfair charging policies and systems that don't recognise or promote access to the expert health and nursing care that people with advanced dementia need.

The contribution of the ASCPP in developing a definition of advanced dementia was crucial to the Commission's work and provides the basis for the main recommendations of the report. The lack of an agreed definition of advanced dementia has been a significant factor in our current, primarily social care, response to advanced dementia and gives rise to two glaring inequities:

- An absence of equality of access to the health and nursing care that is available to people with other progressive and terminal illnesses.
- People with advanced dementia disproportionately impacted by social care charges for what are essentially health and nursing care needs which should be free.

The report recommended recognising advanced dementia as a continuum of living and moving beyond a preoccupation with death and dying (Hanson et al, 2016). This definition enables us to recognise and respond to advanced dementia. In this way we can end these inequalities by ensuring that people living and dying with advanced dementia have access to the free specialist health and nursing care they need on an equal basis with those who have other progressive and terminal illnesses.

The Commission makes the following recommendations:

- That the Commission definition of advanced dementia is used and implemented in practice.
- That advanced dementia is recognised as a continuum which includes but is not confined to end of life and dying.
- That the Scottish Government commits to recognising that the needs of people with advanced dementia are health care needs and ensure equality of access to appropriate health and nursing care, which is free at the point of delivery.
- That the Scottish Government commits to investigating the costs of implementing appropriate and free health care for those living, and dying, with advanced dementia.
- That the Scottish Government, COSLA and Integration Joint Boards commit to ending the current lack of transparency, complexity and variability in current non-residential care charging provisions across Scotland.
- That the recording of dementia (including advanced dementia) prevalence across all health and social care settings is urgently required to support better understanding of demand, allocation of resources and improved care and support.
- That all local authorities/health and social care partnerships make local charging policies accessible and readily available.

The report marked the beginning of one of the most significant campaigns Alzheimer Scotland has ever undertaken. It seeks to ensure that people in Scotland with advanced dementia have equality of access to the expert health and nursing care they need which is free in line with other progressive and terminal illnesses. The Scottish Government have welcomed the recommendations of the Fair Dementia Care Campaign, and are currently considering them. A recent Scottish Parliamentary motion in support of Fair Dementia Care was supported by 53 of the eligible MSPs from all parties in the Parliament. Alzheimer Scotland in partnership with the ASCPP continue to build public and political support with the aim of securing a commitment from each of the main political parties to deliver fair dementia care for people with advanced dementia and their families ahead of the next Scottish Parliamentary elections in May 2021.

Read the full report here and please pledge your support to the campaign

<https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/fair-dementia-care>

## SDRC EXECUTIVE COMMITTEE

Congratulations to Dr Louise Ritchie who has been elected to join the **Scottish Dementia Research Consortium** Executive Committee. Louise was elected as one of three new members of the Executive Committee following a membership vote on 10 nominees in March 2019. Within the Committee Louise will represent Early Career Researchers and will contribute to the development of the Living with Dementia theme, led by Professor Debbie Tolson.

## RCN DEBATE



As part of Scotland's Dementia Awareness Week the Royal College of Nursing Scotland hosted a debate - **'My Right to Nursing': Dementia as a Health and Social Care Issue** on Thursday 6th June 2019. UWS Professor Debbie Tolson, who is a Fellow of the Royal College of Nursing, was part of a panel debating the current landscape, challenges and future possibilities. Other panel members included Archie Noone, chair of the Scottish Dementia Working Group; Muriel Reid, National Dementia Carers Action Network member;

Helen Skinner, Alzheimer Scotland Dementia Nurse Consultant, NHS Fife; and Joanna Macdonald, Chief Officer at Argyll & Bute Health and Social Care Partnership.

During the debate, the role of higher education in preparing nurses with enhanced dementia knowledge and practical skills was explored with reference to the UWS-led workforce development Dementia Champions programme. Drawing on the recent Fair Dementia Care Commission report (see more on this on page 40) and the new Health and Care (Staffing) (Scotland) Bill, Debbie argued that as a society, we need to ask how much we value access to expert nursing and what we are prepared to do to ensure that dementia care is safe and fair for all.

# Selected publications

## SCOTTISH PARLIAMENT: THE ADVENTURE CONTINUES.

### Cross Party Working Group on Dementia

We continue to play a key part in the Cross Party Working Group on Dementia in Edinburgh where people living with dementia, family carers, practitioners and academics meet quarterly to discuss key concerns. Debbie and Margaret attend these and maintain close contact with those attending. Our 'Being Home: Housing and Dementia in Scotland' report was circulated, through this group, to all Health and Social Partnerships. The Group welcomed responses from many of these, but it is clear that while some changes are underway, there are areas for improvement throughout Scotland.

### Helping the Scottish Parliament become dementia friendly

The whole ASCPP team attended the Scottish Parliament on Wednesday 9th October 2019 for a celebration of the Charter of Rights for people affected by dementia. Together with partners the Alliance and Alzheimer Scotland this is part of a drive to support the Scottish Parliament to become Dementia Friendly.

## PEER REVIEWED JOURNALS

Abreu W, **Tolson D**, **Jackson G**, **Staines H**, **Costa N** (2018) *The Relationship between frailty, functional dependence and healthcare needs among community dwelling people with moderate to severe dementia. Health and Social Care in the Community* DOI:10.1111/hsc.126

Campbell, A., Grace, F, **Ritchie, L**, Beaumont, A. & Sculthorpe, N., 26 Feb 2019, Long-term aerobic exercise improves vascular function into old age: a systematic review, meta-analysis and meta regression of observational and interventional studies. *Frontiers in Physiology*. 10, 37

Egdell, V, Cook, M, Stavert, J, **Ritchie, L**, **Tolson, D** & Danson, M. (2019) Dementia in the workplace: are employers supporting employees living with dementia? *Aging and Mental Health* (forthcoming/in press)

Hasemann W, **Tolson D**, Godwin J, Spirig R, Frei IA, Kressig RW (2018) Nurses' Recognition of Hospitalized Older Patients With Delirium and Cognitive Impairment Using the Delirium Observation Screening Scale: A Prospective Comparison Study. *Journal of Gerontological Nursing* 44 (12) 35-43

Knifton, C., **MacRae, R**, **Jack-Waugh, A**, **Brown, M**, Surr, C., Thompson, R. & Baillie, L., Jun 2019, Perspectives: dementia education in Higher Education Institutions, now and in the future: the role of the professional regulatory bodies in the UK. *Journal of Research in Nursing*. 24, 3-4, p. 271-278 8 p.

Peacock, S., Burles, M., Hodson, A., Kumaran, M., **MacRae, R**, Peternej-Taylor, C., & Holtslander, L. (2019). Older persons with dementia in prison: An integrative review. *International Journal of Prisoner Health*. Early Cite <https://doi.org/10.1108/IJPH-01-2019-0007>

**Ritchie, L**, Quinn, S, **Tolson, D**, Jenkins, N, & **Sharp, B**. (2019). Exposing the mechanisms underlying successful animal-assisted interventions for people with dementia: A realistic evaluation of the Dementia Dog Project. *Dementia*, DOI: 10.1177/1471301219864505.

## BOOKS

**Jackson, G.A. and Tolson, D** (eds) (2019) *Textbook of Dementia Care*. Abington, Routledge

## BOOK CHAPTERS

**Brown, M**. and Marshall, T (2018) Care of the frail older adult in Elcock, K., Wright, W., Newcombe, P. and Everett, F. eds *Essentials of Nursing Adults*, London , Sage

**Brown, M**. and Fox, H. (2018) Care of the adult with dementia in Elcock, K., Wright, W., Newcombe, P. and Everett, F. eds *Essentials of Nursing Adults*, London , Sage

**Macrae, R**, **Brown, M**. and **Tolson, D**. (2019) Dementia in Holtslander, L, Peacock, S. and Bally, J. (eds) *Hospice Palliative Home Care and Bereavement Support: Nursing Interventions and Supportive Care* Springer pp 182-197



# The year ahead

## NEW PHD STUDENTSHIP

We were delighted to be awarded funding by Abbeyfield Research Foundation in August 2019 for a PhD Studentship starting in November 2019. Building on our influential 'Being Home: Housing and Dementia in Scotland' report the student will explore the experiences of people with dementia who live in supported housing and how this affects their social, psychological and physical wellbeing. The findings of this work will inform recommendations for research, policy and practice in terms of how supported housing can support people with dementia to live the best life possible.

## DEMENTIA: TOWARDS A MULTI-SPECIES APPROACH

Building on the success of our Animal Assisted Dementia Care: Current Practice & Future Agendas workshop in May 2019, we are delighted to announce we have secured funding from the Wellcome Trust to establish a Dementia and Multi-species international network. Led by Dr Nick Jenkins with collaboration from Dr Anna Jack-Waugh and Dr Louise Ritchie, the network will aim to explore multi-disciplinary perspectives on the role of animals within dementia care and research.

## GROWING INTERNATIONAL COLLABORATIONS

Rhoda is co-investigator on a Canadian Institute for Health Research Grant to 'Champion Health professional dementia education'. As part of the outputs for this project Rhoda and Anna will be travelling to Canada in February to give presentations on dementia education at a two-day stakeholder event. The trip will also provide opportunities to further develop collaborative research between the University of Saskatchewan and the Centre.

Debbie, Louise and Anna continue to work with the team at Manipal Academy of Higher Education in the coming year. The findings of our scoping project (page 38) will inform funding applications to continue work in dementia education and supporting families caring for relatives in advanced dementia in India.

# Class in a Bag Understanding Dementia: Class in a Bag

Class in a Bag is a portable educational resource used to raise awareness of dementia.



Originating from seminal University of the West of Scotland research entitled 'Dementia through the eyes of a child', the resource has been developed and modified to support the exploration of ways to support people with dementia in a number of settings. The educational resource itself includes the physical resources and lesson guides for five experiential interactive workshops. Currently, two different versions of the educational resource have been developed. These are the 'Public and Practitioner', and the 'Schools and Educational Organisations' resources.



This educational resource was the winner of Best Educational Initiative at Scotland's Dementia Awards 2016. Those involved in the Class in a Bag workshops increase their understanding of how dementia may affect people. It also offers an opportunity for those involved to increase their knowledge around alternative way of supporting a person with dementia.

More information and details of the educational resource can be found at [www.uws.ac.uk/about-uws/uws-online-store/](http://www.uws.ac.uk/about-uws/uws-online-store/)

**WINNER OF BEST EDUCATIONAL  
INITIATIVE AT SCOTLAND'S BEST  
DEMENTIA AWARDS 2016**

# The Scottish Dementia Research Consortium (SDRC)



The Scottish Dementia Research Consortium (SDRC) is a network which supports all research in brain health and dementia taking place throughout Scotland.

Scotland has an international reputation for producing high-quality dementia and brain health research across all disciplines. The SDRC's purpose is to champion the world-class work that is already taking place and help develop this research further still by promoting collaboration across institutions and disciplines.

Above all else, the SDRC ensure that the voice and experience of people with dementia and their families are central to all research, policy and development. We want those living with dementia to not only be the focus of research but also ensure that they are represented at policy level in Scotland, the UK and across the world.

There are five areas of research focus in the SDRC, known as themes, which encompass all aspects of dementia research ongoing across Scotland. These are:

**FUNDAMENTAL SCIENCE**

**DIAGNOSIS**

**PREVENTION**

**SCOTTISH DEMENTIA INFORMATICS PARTNERSHIP**

**LIVING WITH DEMENTIA**

Membership to the SDRC is free and is open to anyone with an interest in dementia and brain health research in Scotland. You can find out more and sign up on our website:

[www.sdrc.scot](http://www.sdrc.scot)

You can also keep up to date with the SDRC and our members on Twitter: [@sdrc\\_research](https://twitter.com/sdrc_research)

## How you can get involved in our work

If you have been inspired by our work, there are a number of ways you can get involved.



These include joining us as a critical friend to help influence our research agenda and shape projects in development and advise on project delivery. We operate an involvement approach to student education and welcome offers to meet with undergraduate and postgraduate students to share your insights and challenges. Volunteering opportunities are also available with Alzheimer Scotland.

Many of our students are self-funding dementia education and research so that they can improve their own practice and become dementia care leaders and innovators where they work. We are seeking funding partners to support our work, so if you are interested in making a donation to support a student scholarship or bursary, or provide other programme support, please contact:

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UNIVERSITY OF THE  
WEST of SCOTLAND  
**UWS**







Alzheimer Scotland's Dementia Helpline is open 24 hours a day, 365 days a year.

If you need information or emotional support call 0808 808 3000 or email [helpline@alzscot.org](mailto:helpline@alzscot.org) at any time, day or night.

Thanks to the Dementia Helpline team, nobody has to face dementia alone.



Making sure nobody faces dementia alone.

Alzheimer Scotland - Action on Dementia is a company limited by guarantee, registered in Scotland 149069. Recognised as a charity by the Office of the Scottish Charity Regulator, no. SC022315 160 Dundee Street, Edinburgh, EH11 1DQ. 0131 243 1453. [www.alzscot.org](http://www.alzscot.org)

We hope you've enjoyed reading about the Centre's work in 2019 and are excited to see what we can achieve together in 2020.





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