

UNIVERSITY OF THE  
WEST of SCOTLAND

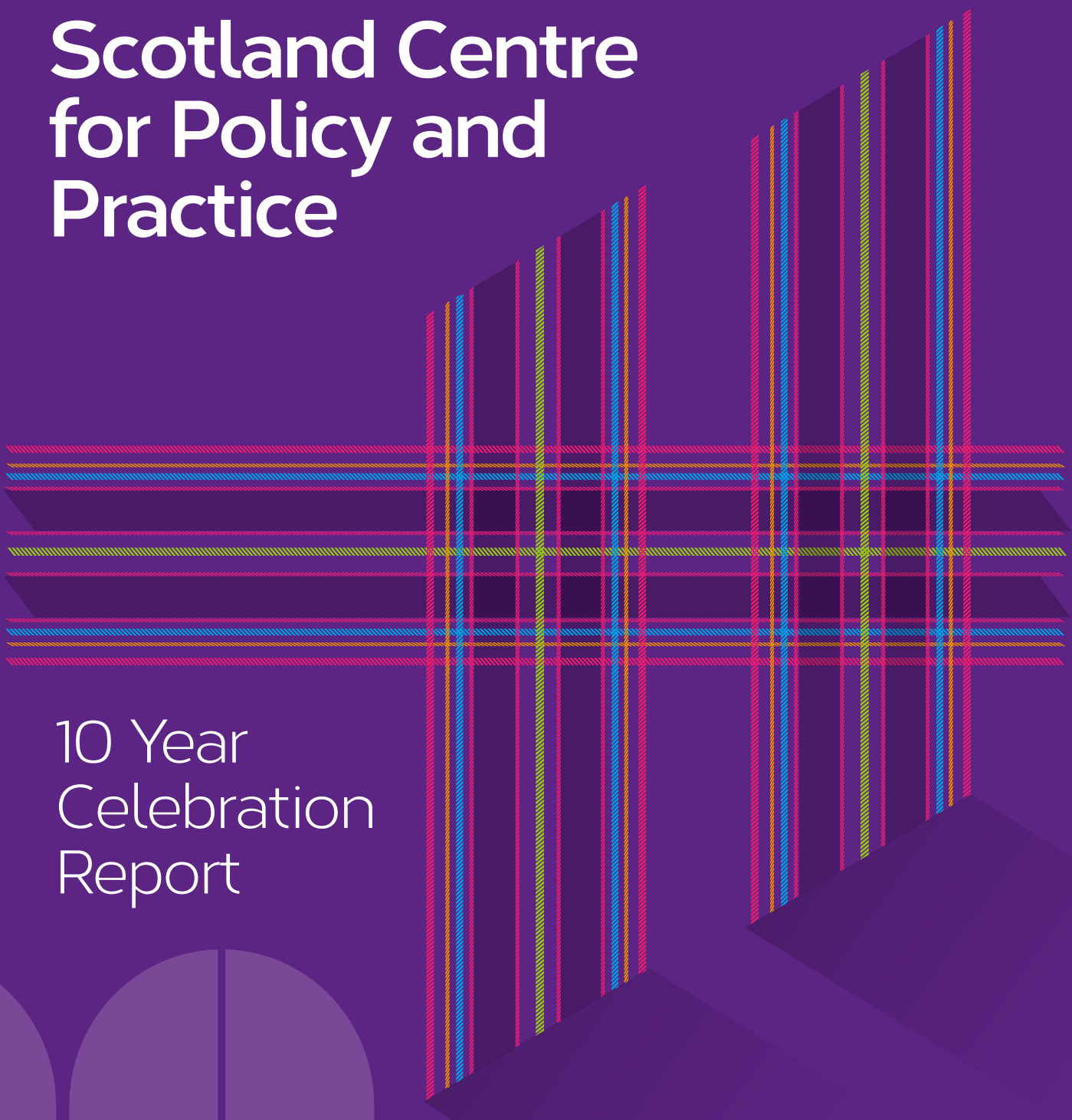
UWS



**Alzheimer  
Scotland**  
Action on Dementia

# Alzheimer Scotland Centre for Policy and Practice

10 Year  
Celebration  
Report



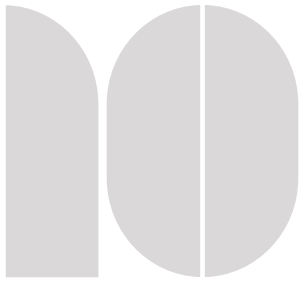


## Our partners



**Alzheimer  
Scotland**  
Action on Dementia





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# Principal's welcome

At University of the West of Scotland (UWS), we are passionate about transforming the lives of our students and society for the better. Since opening in 2013 the Alzheimer Scotland Centre for Policy and Practice has been a force for driving excellence in innovative practice-based education and applied research research in dementia care.



“Cutting edge dementia education and workforce development approaches, pioneered at UWS, are equipping the next generation of leaders to improve practice and services locally and internationally.”

I congratulate the students, staff and our partners for the positive impact of their scholarship on policy, practice and our communities. As Principal and Vice Chancellor, I am very proud to be celebrating the Centre's ten-year anniversary.

Addressing global challenges is core to the UWS Strategic Mission and there is no doubt that dementia is a major public health challenge. Cutting edge dementia education and workforce development approaches, pioneered at UWS, are equipping the next generation of leaders to improve practice and services locally and internationally. Impactful, internationally leading dementia research embodies UWS's commitment to the United Nations Sustainable Development Goals. Tackling the difficult questions and care needs that matter to people living with dementia.

A university flourishes on partnerships with a range of stakeholders, and we value our long-standing collaboration with Alzheimer Scotland. Sincere congratulations to the Inspiring People and Inspiring Practice Award recipients who have worked with the ASCPP team and shared their wisdom. Thank you for being part of our University community as we tackle some of the world's greatest challenges.

**Professor James Miller**

Principal and Vice-Chancellor,  
University of the West of Scotland

# 10 years in numbers



**68** Journal articles published

.....

**11** Book chapters

.....

**2** Edited books



**28** Research grants - £1.2m

.....



**25** Enterprise grants - £1.1m

## International collaborations in

India, Canada, Czech Republic,  
Poland, Portugal, Spain  
Sweden, Netherlands



**1 REF2021**  
Research Excellence Framework  
Impact Case Study

**11**  
Awards

**75+**  
Conference presentations

**1** New MSc programme



**Class in a Bag**



**50+** MSc enrolments



**14** PhD students

**10,000**  
school pupils

**1100+** Dementia Champions



**1500+**  
CPD Course attendees

**2,400**  
student nurses



# Director's welcome



In January 2013 I joined UWS as the inaugural Director of the new Alzheimer Scotland Centre for Policy and Practice (ASCPP). A decade later, myself and the ASCPP team have much to celebrate and many people to thank and acknowledge. The partnership with Alzheimer Scotland and contributions of their staff and members, makes for an exceptional learning environment for all of our learners; pre- and post-graduate students; staff and carers. The list of individuals is too long to include names in this brief welcome. But to all of you who have contributed to our dementia education as co-educators, either through research involvement, or as co-researchers and via participation in our Open Meeting and ASCPP events, I'd like to extend a sincere and heartfelt thank you. You keep us grounded, you challenge us and you connect us to your everyday realities. This ensures our scholarship is wanted, relevant, practical and helpful.

To mark our ten-year anniversary, we are honouring three groups and one individual. The groups receiving **Inspiring People Awards** are the Scottish Dementia Working Group (SDWG), National Dementia Carers Action Network (NDCAN) and the Alzheimer Scotland Dementia Consultant Group. The individual **Inspiring Practice Award** goes to Margaret Callaghan. She exemplifies our goal that ASCPP dementia education pathways advance practice careers and simultaneously improve lives. Congratulations to all receiving celebratory medals and thank you for the difference you are making to so many.



From the outset, the primary focus of our Centre has been research-informed ***Dementia Education for All***. One of our early imperatives was to establish a distinctive approach to dementia education excellence. Accordingly, our signature pedagogy: Care Empathia, is a theory and research-based approach to dementia education, which impacts and changes how people *think, feel* and what they *do* about dementia. More recently, we have added 'trauma-informed' know-how to the mix. This has created supportive learning spaces for family carers, volunteers, students and practitioners to make sense of difficult experiences and move forward with positivity.

The ASCPP's awarding-winning approaches to dementia education is within UWS undergraduate programmes, and it enables our nursing students to qualify at the skilled level of the NES Framework for Excellence (FfE 2021). We are currently supporting the nursing faculty at Manipal Academy of Higher Education, India, to embed dementia practice education within their undergraduate courses.

Since 2011, we have driven up standards of hospital care by preparing over 1,100 Dementia Champions to practice at the enhanced level (FfE). The Scottish Government-funded Dementia Champions programme is delivered by UWS in partnership with Alzheimer Scotland. It is recognised as one of the UK's 100 best breakthroughs by Universities UK, for its significant impact on people's

everyday lives. Collaborations with the University of Saskatchewan are underway to research and establish similar approaches within Canada.

Our contribution from 2017 to the learning of the Dementia Specialist Improvement Leads – in partnership with NHS Education for Scotland – equips mental health practitioners to become leaders in their field and reach expert level (FfE).

In partnership with NHS Ayrshire and Arran, we have pioneered the ASCPP Carers' Academy, and established an additional hub with NHS Lanarkshire, with more being planned. The model provides family carers with access to a unique, university skills-based learning experience within state-of-the-art skills facilities.

In 2020, we were awarded an Advanced HE Collaborative Award for Teaching Excellence (CATE) for our groundbreaking Class in a Bag. Class in a Bag is a portable intergenerational education resource used by student nurses to teach school children. More than 10,000 children have learned from over 2,400 nursing students about dementia and have pledged to be dementia positive citizens.

Informing our dementia education are two major thematic research programmes: ***Living the Best Life Possible*** and ***Dementia Education for All***

Building research programmes and research capabilities takes time and we have steadily grown – and continue to grow – our applied dementia research community at UWS. Executive leadership roles within the Scottish Dementia Research Consortium demonstrate how far we have come in terms of our research confidence and productivity. Thanks to RS MacDonald Charitable Trust funding, we now have a dedicated UWS Seedcorn Fund, to support preliminary studies designed by academics new to dementia research. This also enables new dementia researchers to experience the benefits of research involvement. The ASCPP best practice approaches to research involvement with family carers has been showcased by Alzheimer Disease International in their 2021 Plan to Impact Report, which was launched at the recent World Assembly <https://www.alzint.org/u/From-Plan-to-Impact-IV.pdf>

For research to be useful, it must have impact. There are so many examples I could list of both the small and major differences our research is making. We are, however, particularly proud that our dementia research impact case study was selected by the University for the Research Excellence Framework (REF) 2021 submission. REF is a national exercise to determine the quality and impact of academic research. The contribution of our research to the United Nations Sustainable Development Goals was a featured case study in The SDG Accord 2022 report ([https://www.sustainabilityexchange.ac.uk/sdg\\_accord\\_report\\_2022\\_case\\_studies](https://www.sustainabilityexchange.ac.uk/sdg_accord_report_2022_case_studies)).

As my note of welcome shows, it has been a busy and rewarding ten years. Moving forward, some things will change, but our mission will remain steadfast: to use ASCPP collaborative scholarship to make the world a better place for people living with dementia.

**Professor Debbie Tolson**

PhD MSc BSc (Hons) RGN FRCN PFHEA

School of Health & Life Sciences

Alzheimer Scotland

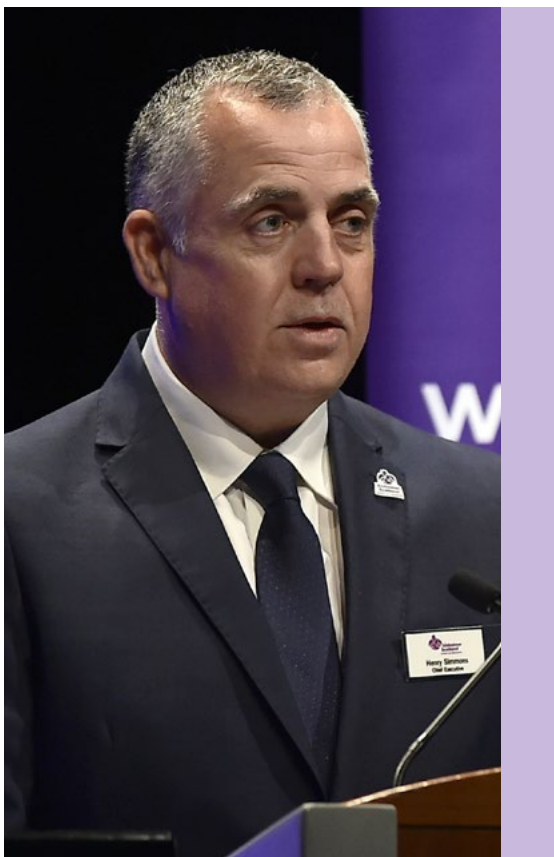
Professor of Dementia

Director of the Alzheimer Scotland  
Centre for Policy and Practice





# Alzheimer Scotland Chief Executive's welcome



It is a great privilege to welcome you to the Alzheimer Scotland Centre for Policy and Practice 10 year Celebration Report. It feels like no time since we had initial conversations with the then Head of Faculty at University of the West of Scotland (UWS), Paul Martin. We were so impressed by UWS's deep desire to make a substantial commitment to improve the lives of people with dementia and their families and carers. The potential scale of the number of future professionals that would benefit from an improved understanding on how best to support people with dementia was a fantastic opportunity which we had many hopes and ambitions for. Looking back, it's clear these hopes and ambitions have not only been met, but indeed have been surpassed.

The partnership with UWS and the Centre has made a remarkable contribution - not only has it transformed the number of nurses graduating at a higher skilled level of dementia practice, there has also been a revolution of our general healthcare system, with over 1000 Dementia Champions. This deep understanding of dementia, alongside the workforce development tools provided by the Promoting Excellence Framework, has enabled a systemic shift in the paradigm of understanding of dementia in our general hospitals. Undoubtedly the pandemic had an impact on some of this work, but we are certain this will be recovered due to the knowledge, skills, expertise and tenacity of the Centre's team.

The Centre has been the vanguard of translating our policy and campaigning work into practice and has led on some remarkable innovations, from the Carers' Academy to Class in a Bag, and it has informed some of our most significant reports, such as our 2019 Fair Dementia Care commission. The Centre has also demonstrated a commitment to shine a light on areas such as the prison population, tackling issues often neglected in terms of research focus.

The voices of those with lived experience are at the heart of the values and principles underpinning the aims of the Centre, working very closely with members of both the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Actional Network (NDCAN). Well done to the groups for their contributions to the Dementia Champions programme and research projects. This has led to their 'Inspiring People' award, alongside Alzheimer Scotland's Dementia Consultants for their leadership in practice and contributions to teaching, and Margaret Callaghan for her inspiring practice too – truly well deserved awards.

Congratulations on this 10 year celebration. We cannot commend the Centre enough for making the best of this partnership and their substantial return on the small investments Alzheimer Scotland has made to support this work. We are incredibly grateful and look forward to continuing to build on this wonderful partnership.

**Henry Simmons**  
**Chief Executive, Alzheimer Scotland**

# About the Centre

The Alzheimer Scotland Centre 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 dementia education and research based scholarship. We work collaboratively through a range of partnerships in practice and with involvement of people whose lives are affected by dementia.

ASCPP is located within the School of Health and Life Science, reaching across all academic schools. Our main base is located at the award-winning UWS Lanarkshire Campus: winner of the Guardian University Award 2019 for Buildings That Inspire. Our students also benefit from the award winning DOMUS facilities on every campus. DOMUS is a simulated domestic environment, in which students can experience the latest high and low tech aids for living and care. Adjacent to the DOMUS are the hospital simulation suites, Acorn Primary Care area and Living Lab. Our pioneering dementia education extends from our Spiral Curricula and Discover Dementia within pre-registration nursing and mental health nursing programmes, through our taught masters (MSc in Dementia Care), and independent research degrees - MRes, MPhil and PhDs. Our impactful research focuses on two thematic areas, Dementia Education for All and Living the Best Life Possible.

We are proud of our dementia leadership contributions within both the UK Higher Education Dementia Network and the Scottish Dementia Research Consortium.

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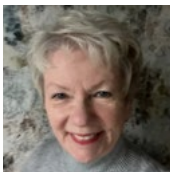
# Meet the team



## **Professor Debbie Tolson, Director**

Debbie is the Alzheimer Scotland Professor of Dementia and ASCPP Director. She is a registered nurse, Fellow of the Royal College of Nursing and Principal Fellow of the Higher Education Academy (UK). She has a particular interest in research and educational innovations that recognise dementia as a family illness experience and are of practical value. Through her UWS role and executive role with the Scottish Dementia Research Consortium, she is supporting the next generation of dementia leaders and researchers to flourish.

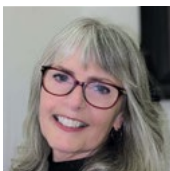
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## **Dr Margaret Brown, Depute Director**

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.

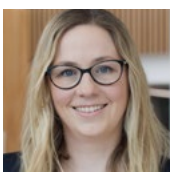
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## **Dr Rhoda MacRae, Reader**

Rhoda takes a lead role in research and enterprise activities within the Centre. Her research interests include dementia in secure settings and dementia education. She is currently leading a research study into dementia in prison and assessing the feasibility of introducing cognitive screening in prisons. She also leads an Institutional Seedcorn Fund designed to grow interdisciplinary applied dementia research at UWS.

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## **Dr Louise Ritchie, Reader**

Louise leads on our dementia in the workplace research in the Centre. She has a background in psychology and her research interests include young onset dementia, housing, research involvement and co-production methods. She is an Executive Committee member of the Scottish Dementia Research Consortium. She is currently leading on an Alzheimer's Society funded 3-year project co-producing an intervention for people who are diagnosed with dementia whilst in employment.



### **Dr Anna Jack-Waugh, Senior Lecturer**

Anna leads on developing interprofessional education through research and practice for all health and social care staff working with people with dementia. Anna has been involved in projects on advanced dementia across Europe and collaborated with colleagues in India and Canada to learn from Scotland's National Dementia Champions on an international stage. In addition, Anna teaches and leads the integration of dementia education in undergraduate and postgraduate nursing and paramedic programmes at UWS.

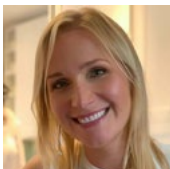
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### **Dr Raymond Duffy, Lecturer**

Raymond is currently the Programme Leader for MSc Dementia Care at UWS. 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.

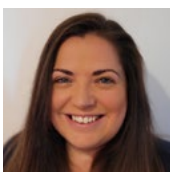
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### **Dr Eileen Harkess-Murphy, Lecturer**

Eileen is a psychologist who has an interest in psychological trauma and how trauma-informed approaches can mitigate risk of re-traumatisation for carers and people with dementia. She has expertise in medical statistics and data analysis and has recently led on a Scottish Neurological Research Fund project working with leading experts in the field of trauma and dementia that explores the experiences of carers and people with dementia through a trauma-informed lens and hopes to develop this work in the field of trauma and dementia in the future.

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### **Dr Natalie Chalmers, Research Fellow**

Natalie is a Postdoctoral Research Fellow working on the Dunhill Medical Trust project improving the health and well-being of older people with dementia in prison. Her research interests include secure settings, mental health and intervention development.



### **Dr Laura Lebec, Research Fellow**

Laura is a Post-Doctoral Research Fellow and is supporting the Alzheimer's Society action research project which is co-producing careers guidance intervention for people living with dementia. Laura's background is in the third sector where she has worked for social care organisations supporting both adults and children. Her research focus has been about driving improvements to the quality of care in social care services and she is particularly interested in integrating person-centred approaches to research.

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### **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.

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### **Professor Iva Holmerová, Visiting Professor**

Iva is an Associate Professor and CEO of the Centre for Gerontology, Praha 8. She was also the Chairperson of Alzheimer Europe. Iva is our visiting Professor at the Centre and a Palliare partner and currently supporting International Student Networking Conversations.

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### **Dr Graham Jackson, Emeritus Professor**

Graham 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.

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**A list of our Centre Associates can be found at**  
[www.uws.ac.uk/research/research-institutes-centres-groups/alzheimer-scotland-centre-for-policy-and-practice/meet-the-team/](http://www.uws.ac.uk/research/research-institutes-centres-groups/alzheimer-scotland-centre-for-policy-and-practice/meet-the-team/)





# ASCPP through the years

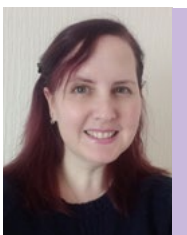






# Doctoral students progress and updates

We are so proud of the achievements of our students, past and present. Over the years, we have supported 14 PhD candidates. Students who have since graduated with their doctorates still stay in touch with us and we are delighted to report have all went on to begin successful careers in academic institutions, third sector and government and clinical roles. Below our current students share their own progress updates.



## **Rachel Allen, UWS Studentship**

I am grateful to be part of the research team at UWS and ASCPP, thanks to funding through a UWS Studentship for my PhD exploring young onset dementia and career. The supervisory team for my PhD is Dr Louise Ritchie (Lead Supervisor), Dr Emma Bolger and Professor Debbie Tolson. During my first year I have been reading and reviewing the relevant literature, defining the methodological aspects of my research, and drafting my research questions. I am looking forward to beginning data collection in 2023. I plan to interview women living with young onset dementia about their careers, focusing on the roles that are part of career experience. This includes roles in paid work as well as in the family, community and beyond. I am excited about the potential for my research and the contribution it will offer.

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### **Carol Beckwith**

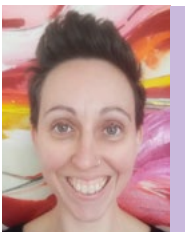
With a background in psychology, music, and song writing, I enrolled as a part-time PhD student in October 2020.

My research uses narrative inquiry and art-based research methods, and aims to explore the experiences of those who care for someone with dementia by engaging in group storytelling and song writing activities with groups of carers.

Using these narrative and creative practices can help make it easier for carers to talk about their experiences, thoughts, and feelings, by creating safe spaces where they can find alternative ways of expressing themselves.

Having recently received ethical approval to proceed with my research, my next steps will be focused on participant recruitment and then to begin data collection and I am very much looking forward to this next stage.

As I am part-time and self-funding, I also work as a Health Improvement Senior in Public Health, and I am a freelance community music practitioner.



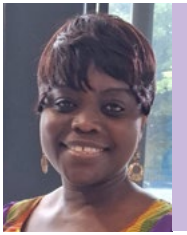
### **Angela Gregory, Erskine, Alzheimer Scotland and UWS Scholarship**

I am an HCPC registered occupational therapist with a background as a freelance artist-educator and singer. My PhD is funded by UWS, Erskine and Alzheimer Scotland, with additional backing from the Scottish Dementia Research Consortium.

My research aims to understand the concept of meaning in activities and interactions with people living with advanced dementia in a care home setting. Using Action Research and creative methods, I worked directly with people living with advanced dementia doing everyday activities such as walking, eating, and dancing, in addition to observations of visits, interviews with family members and focus groups with staff. I later completed a workshop with families and staff to explore early findings and I am currently analysing the data with supervisory support.

Furthermore, I have contributed to the research and learning within ASCPP, including teaching on undergraduate programmes and the Dementia Specialist Improvement Leads programme, and working as a research assistant. Dr Margaret Brown and I have recently published a book chapter in 'Occupational Therapy and Dementia'.

## Doctoral students **progress and updates**



### **Margaret Kyeremeh, UWS Studentship**

I am excited to undertake a funded PhD in dementia research at the ASCPP at UWS. This studentship is funded by the Vice Chancellor's Fund at UWS. My background is in nursing and social work, and I am a Dementia Champion with experience working with people with dementia and family carers.

I commenced my PhD in October 2022 and am fortunate to work with Dr Anna Jack-Waugh (Lead Supervisor), Dr Nick Jenkins, and Suzanne Heron. My research focuses on understanding the experience of managing risk from the perspectives of family carers of people living with advanced dementia. Using the constructivist grounded theory approach, the research will explore practical solutions family carers employ to manage risk situations within the family home.

Over the coming months, I will develop a literature review protocol and research proposal of *"Everyday solutions deployed by family carers when balancing risks and safety of people with advanced dementia living in the family home"*. I am enthusiastic about leveraging these findings within the areas of risk perceptions and risk solutions and developing resources for improving outcomes for family carers.

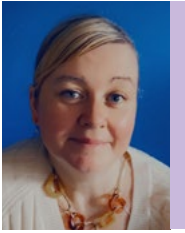
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### **Mohammad Mollah, Bangabandhu Overseas Scholarship**

I started my PhD in December 2019, funded by the Bangabandhu Overseas Scholarship Program. My study aims to investigate and analyse Scottish dementia care policies and workforce development approaches to determine the utility for application in Bangladesh.

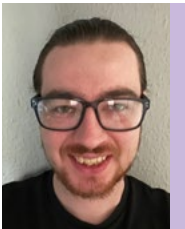
An integrative literature review and a critical review of the development and implementation of dementia care strategies in Scotland and Bangladesh is complete. In addition, a Documentary Policy Analysis has been prepared to critically evaluate the dementia policy success in Scotland. Data collection has been undertaken from the key policy stakeholders in Scotland and the Nominal Group Discussions with stakeholders in Bangladesh, and the data analysis is in progress. I completed my Annual Review Progress in June 2022 and presented two posters based on my PhD study design at the SDRC (Scottish Dementia Research Consortium) Annual Conference in May 2022 and the UWS Annual Research Conference in June 2022. My final year PhD study focus will be completing the final set of stakeholder interviews from Bangladesh, reporting, and writing the thesis.



### **Yvonne Manson, Funded by Holmes Care**

I am a part-time research student who works full-time as the Head of Dementia and Lifestyle Enhancement at Holmes Care covering 22 care homes across Scotland. My study focuses on partnership working with families in care homes and is a constructivist grounded theory. Commencing a PhD while working full-time on the front line during a pandemic has brought its own challenges but I am very fortunate to have an excellent supervisory team. Having worked collaboratively with people with dementia and their families in care homes throughout my almost 30-year career, I am excited to have the opportunity to now be exploring the experiences and understanding of partnership working in practice in care homes as a researcher. I feel very fortunate to be fully funded by Holmes Care and to be on this journey.

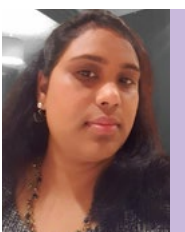
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### **Connor McDonald, Wendy Baxter Scholarship**

I am a second year PhD student based at the ASCPP at Lanarkshire Campus. I am grateful to be the recipient of the Wendy Baxter Scholarship for my PhD thesis researching the potential benefits of family-led, individualised reminiscence delivered during care home visits with people living with advanced dementia. Over my first year I presented a poster outlining my thesis ideas as part of the UWS Research Festival Poster Competition and presented a more in-depth overview of my study during an ASCPP Open Meeting. Both of these were great opportunities to practice presenting my study to different audiences as well as gathering thoughts and feedback from family carers. Over the next year I aim to start my data collection with family visitors and begin to work together to co-create our approach to reminiscence.

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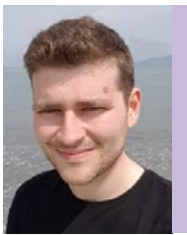


### **Vino Murugavel**

I am delighted to join the ASCPP and the dementia research team at UWS as a part-time research student this year. I completed my MSc in Mental Health Nursing at UWS in 2018 and worked as a community mental health nurse for older adults. My PhD supervisors are Dr Eileen Harkess-Murphy (Lead), Dr Marie McCaig and Dr Margaret Brown. My research interest is in trauma-informed care and dementia.

Dementia is a global threat, and a national priority as the numbers are set to triple to 132 million in 2050. Although the studies to establish the link between trauma and dementia are slowly on the rise, little is available to understand the carer's knowledge, skill, and attitude toward trauma-informed care. Therefore, my research interest is in trauma-informed care for people with dementia to reduce carer stress.

# Doctoral students **progress and updates**



## **Michael Smith, Abbeyfield Research Foundation Studentship**

Funded by the Abbeyfield Research Foundation, I began my PhD in November 2019. My research focuses on the experience of living with dementia in supported housing in Scotland.

For the first stage of my research, I conducted a systematic literature review that aimed to understand how living in supported housing influences the lives of people with dementia. This was published in the journal of Health and Social Care in the Community.

The second stage of my research aims to develop a deeper understanding of the experience of living with dementia in supported housing in Scotland, through multiple-case study research. Six case studies were conducted in supported housing settings. An additional case study sought to understand perceptions on supported housing as a future housing choice for people with dementia. I am currently completing data analysis for this stage, and hope to submit my thesis for examination later in 2023.

# Our inspirational award winners

In previous years, we have awarded the University of West of Scotland Celebration Medal 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. Pandemic restrictions have meant that we have been unable to host our usual named celebration lecture for the last few years. We are delighted this year to welcome our colleagues, partners and friends back to the University to host a Celebration Event for such an important anniversary for the Centre. As we looked back over 10 years, we found it difficult to nominate just one person who had inspired us over the decade. Instead, this year we award three **Inspiring People** medals and one **Inspiring Practice** medal. All of the recipients have made important contributions to the work of our Centre and we look forward to celebrating with them.

In our inaugural celebration lecture and report in 2017, we recognised the contribution of Henry and Anne Rankin for their dedication to working alongside us in the Dementia Champions programme and other innovations. Henry is sadly no longer with us, but his legacy continues to impact our work. In 2018, we recognised the impact Jenny Henderson has made throughout her career in leading through courage, innovation and service to improve the lives of those affected by dementia, particularly around end of life care. The Annabelle Gray Celebration Lecture in 2019, celebrated Annabelle, wife of the late Bill Gray, for her dedication to embedding the voice of family carers within the nursing curriculum, and her role in supporting the ASCPP Carer's Academy. Instead, 2020's report shared inspirational stories about excellence and innovative dementia related practice during the lockdown period. In 2021, we highlighted innovations in dementia education and their impact on practice. This year, we are delighted to introduce the recipients of the Inspiring People and Inspiring Practice medal winners. We look forward to celebrating their contribution to our Centre with our students, partners and colleagues.

# Inspiring People

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## SCOTTISH DEMENTIA WORKING GROUP

The Scottish Dementia Working Group (SDWG) is a national, member led campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. Members of the group have inspired, supported and contributed to our teaching, research and policy influencing activity in the Centre and we are delighted to award this Inspiring People medal to the group.

As part of the teaching team on the Dementia Champions Programme, members of the Scottish Dementia Working Group have inspired our staff and students alike. The contribution of members of the Scottish Dementia Working Group is consistently reported as a highlight of the programme by Dementia Champions.

We are incredibly grateful for Scottish Dementia Working Group members, past and present, for their contributions to our research. Members are invaluable to our research projects, as advisors, co-researchers and critical friends to our students. They help us to ensure that our research is relevant, useful and can make a meaningful difference to the lives of those living with dementia.

Involvement of people living with dementia is at the heart of our work in the Centre. We are honoured to have had such constant support from the Scottish Dementia Working Group in these first 10 years. They inspire our work each and every day and we are delighted to celebrate this with the award of this Inspiring People medal.

“The SDWG are truly honoured by this award. As a group, working alongside academics, we can make a meaningful difference to the understanding of dementia. We have a partnership in which lived experience is integrated and valued as an equal part of research. The SDWG wants to make a contribution and UWS gives us that opportunity. Long may the partnership continue.”

**Margaret Northedge, Scottish Dementia Working Group**



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## NATIONAL DEMENTIA CARERS ACTION NETWORK

The National Dementia Carers Action Network (NDCAN) exist to make the voices of carers heard and raise awareness of the issues impacting carers. Throughout the last decade, members of National Dementia Carers Action Network have worked closely with us to ensure that the voices of carers are heard throughout our Centre activities.

As members of the teaching team on the Dementia Champions programme, National Dementia Carers Action Network members have supported our learners to understand and value the role of family members in supporting a person with dementia in hospital settings. As co-researchers and members of project advisory groups, they have made important contributions to the development and dissemination of research within the Centre. Members of the National Dementia Carers Action Network have formed a research sub-group and are supported by members of the Centre to develop their own research ideas and projects. In 2022, we celebrated a success of this partnership as we were awarded funding through the UWS Studentship fund for a co-produced research project exploring risk from the perspective of family carers.

We are delighted to be awarding this Inspiring People medal in recognition of the contribution of the members of National Dementia Carers Action Network to our Centre.

“ Too often policy and practice seem completely unrelated. All of the ground breaking work and innovative research that comes out of the ASCPP at UWS brings policy and practice together in the real world. ”

“ NDCAN are extremely honoured to be recognised and awarded by the ASCPP - a powerhouse - that our members hold in high esteem for their inspirational work which drives much of our campaigning and ideals. ”

Thea Laurie, National Dementia Carers Action Network



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## ALZHEIMER SCOTLAND DEMENTIA CONSULTANTS

The Alzheimer Scotland Dementia Consultants are specialist nurses and allied health professionals working across Scotland. In awarding this medal we are recognising and celebrating their ongoing relationships and collaboration with the Alzheimer Scotland Centre for Policy and Practice. Their individual and group collaborations with the Team have ranged from local education of postgraduate students to national programmes for the Dementia Champions and Dementia Specialist Improvement Leads. They have been pivotal in innovations such as Care Empathia development and core to our Carers' Academy. In our research projects they contribute to our success with their practice knowledge and experience, creating research that is meaningful and applied for people living with dementia and family carers. These relationships have resulted in transferring knowledge gained from education into practice delivered by health and social care staff.

Many of the Alzheimer Scotland Dementia Consultants have taught in partnership with the Dementia Champions faculty over a number of years, and in doing so they support Champions to contextualise their learning to local services and people with dementia in their local areas of care. For the Dementia Champions who are often lone voices for change within complex systems, the Dementia Consultants provide a lynchpin, knowledge source, signposting and support to enable Dementia Champions to be their best.



# Inspiring Practice

## **MARGARET CALLAGHAN, NURSE AND DEMENTIA CHAMPION**

The Inspiring Practice Medal is awarded to a practitioner, and UWS graduate who is making an exceptional contribution through promoting positive dementia practice, which is at the heart of ASCPP dementia education. Nearly ten years ago, Margaret was one of the first to complete our Postgraduate Certificate in Working with Older People. Subsequently she completed our MSc and despite her full-time practice role as a senior care home nurse, she successfully published her dissertation findings with her supervisor. Although clearly already an expert in nursing with older people, she was determined to excel in dementia care and leading change. She celebrated graduation from the UWS Dementia Champions Programme in 2020 endorsing her standing as a champion of change committed to the highest quality of care for people living in care homes with dementia. Already an impressive ambassador for the transformational impact of ASCPP dementia education on practice, during the pandemic she remains in touch with us exploring possible research directions. True to form however, she went the extra mile stepping in and literally moving into care homes to ensure positive leadership to protect vulnerable care home residents from the risks of the pandemic during lockdown. The care homes she managed during lockdown had zero COVID-19 cases. Margaret has shown outstanding leadership for nursing in care homes, through one of the most extraordinary periods we have experienced. Her exceptional standards for people living with dementia, their families and staff are inspirational. She embodies the spirit and capabilities of UWS graduates.



# Dementia education for all

Our award-winning learning and teaching approaches in the Centre are available for all those people who live with, support, practice, research, and manage care for people living with dementia. We teach masters and doctoral research students and practitioners across health and social care, family carers and citizens of all ages, including older people and schoolchildren. We do this through an imaginative range of learning opportunities, bringing evidence to practice through our signature pedagogical approach, *Care Empathia*, which forms the foundation of our learning and teaching, and influences what we teach, how we teach, and what is learned. This solid foundation creates the conditions to deepen understanding, connection, practical actions, and solutions by encouraging learning via the heart, the head and the hands.

Over the last 10 years we have developed learning materials with family carers, such as the film 'This worked for me', about caring and advanced dementia. We have worked with students and schoolchildren to produce the 'Class in a Bag', our portable learning resource for children and adults. We have also designed large-scale programmes such as Scotland's Dementia Champions programme for the NHS and the SSSC and an extensive suite of learning opportunities including:

- PhD studentships
- MSc in Dementia Care
- Discover Dementia for undergraduates
- Continuing Professional Development
- Bespoke learning for organisations
- The Carers' Academy
- Class in a Bag





The MSc in Dementia Care (formerly the MSc Gerontology with Dementia Care) is the postgraduate teaching programme associated with the Centre. The MSc in Dementia Care has been designed to cater for a range of professionals with relevant experience and interest in working with people living with dementia. Three of the core modules in the MSc Dementia Care programme were developed as outputs from the Erasmus+ K2 Strategic Partnership Palliare Project (2014-2016), ensuring direct transfer of research into teaching and learning and included in our REF2021 ICS.

In addition, we have demonstrated the translation of research to education through the award-winning Dementia Spiral (Discover Dementia), which embeds our research-propelled dementia education throughout the undergraduate pre-registration nursing, paramedic, and sports studies programmes here at UWS. The ASCPP education specialists are members of the Higher Education Dementia Network (HEDN), thus contributing to and influencing the evidence base for high-quality dementia education and training.



The ASCPP is committed to ensuring the translation of research to practice through our signature pedagogical approach, Care Empathia. Care Empathia was developed with a profile that has transferred into the continuous professional development programmes commissioned by NHS Education Scotland (NES) and the individual health and social care partnerships we currently work with. All the continuing professional development programmes use ASCPP's original research and are aligned to the Scottish Government's (2021) Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families, and carers.

We are also commissioned to lead the complex care and trauma-informed aspects of the Dementia Specialist Improvement Leads programme (DSILs) by NES (creating over 100 specialist practitioners educated to Promoting Excellence Expertise level). ASCPP and Alzheimer Scotland collaborate to develop the Scottish Government-funded Dementia Champions workforce development programme. There are now over 1,000 Dementia Champions who are educated to Promoting Excellence Enhanced level, which was recognised as one of the UK's 100 best breakthroughs by Universities UK for its significant impact on people's everyday lives. ASCPP provides bespoke CPD programmes with multiple NHS and Integrated Health and Social Care Partnerships; these include Care Empathia skill development days, Care Empathia leadership development programmes and the Dementia Champions programme at 'Promoting Excellence' skilled level.

'Dementia Education for All' is one of our themed areas of work. This demonstrates a commitment to continued development, refinement and research into effective education strategies in all areas where people with dementia and their families are, in Scotland, the UK and internationally.





# ASCPP Carers' Academy

Family and informal carers have long made a significant contribution to the care of people with dementia and continue to be the foundation of dementia care in Scotland. The number of unpaid carers of people with dementia increased by over a third during the COVID-19 pandemic, with many carers doing more and experiencing increasing levels of physical and psychological distress (Scottish Government, 2022).

The need to provide access to safe and supportive dementia education for family carers has arguably never been greater, and is something we can and should do. The national Dementia Care Standards (<https://www.gov.scot/publications/standards-care-dementia-scotland-action-support-change-programme-scotlands-national-dementia-strategy/>) (Scottish Government, 2011) mean local authorities and the NHS must provide people who have been recently diagnosed and their family carers with educational resources. However, written information on its own is only a starting point. At the Alzheimer Scotland Centre for Policy and Practice, we are passionate about providing innovative and accessible dementia education for all. In 2014 we co-produced a video for carers called 'This Worked For Me...' in collaboration with NHS Lanarkshire and Dumfries and Galloway. Our research highlights that family carers need dementia education and practical skills training, delivered at the right time for them with know-how and sensitivity.



*Scotland's Dementia Awards (2019)  
Winner of Best Educational Initiative*



*Mental Health Nurse Forum Awards (2019)  
Winner of Innovation in Education Award*

Our Carers' Academy is a bespoke educational programme which supports both the information and practical skills-based learning needs of family members caring for a relative with dementia. With the support of Alzheimer Scotland funding, the double award-winning programme was established in 2019, in partnership with NHS Ayrshire and Arran, at University of the West of Scotland's (UWS) Ayr Campus. In 2022, an additional NHS Lanarkshire, Carers' Academy hub was established at UWS's Lanarkshire Campus.

Our work to date offers a blueprint for future service development and will support the joint ambition of the ASCPP and Alzheimer Scotland, to develop a further three Carers' Academy hubs within Scotland, over the next 12 months. Alzheimer Scotland Dementia Consultant's will remain key partners in programme delivery and design. Our carer-informed development board and programme ethos, will also remain a significant driving force in shaping future programme development and evaluation. Annabelle Gray a family carer and board member tells us below the importance of carer representation in this work and its personal meaning to her:

“It is a pleasure to be a member of the Carers' Academy Development Board and to be able to have ongoing input to this work from a family carer perspective. I find it very rewarding being able to share my experience and contribute to such a valuable support strategy”

As part of our 10 year celebration event, we would like to thank all the partner agencies who contribute to the development and delivery of this unique programme. We value the commitment of the family carers who are members of the Carer's Academy Development Board and thank you for sharing your expert insights and giving so generously of your time. Thank you also to all the family carers of people with dementia, who have put their trust in us. We are extremely proud of all the ASCPP Carers' Academy stands for and its work to date and are excited to see our ambitions realised over the coming years.

#### **THE ASCPP CARERS' ACADEMY LEADERSHIP TEAM:**

**Susan Holland**, Alzheimer Scotland Dementia Consultant,  
Ayrshire and Arran NHS

**Margaret Brown**, ASCPP Depute Director, UWS

**Debbie Tolson**, ASCPP Director, UWS



# Research with impact

Research drives the impact of the Alzheimer Scotland Centre for Policy and Practice. An important feature of our Centre activity is the development of applied research. Over the years, listening to the concerns of people whose lives are affected by dementia has enabled us to build two key programmes of impactful research:

- Living the Best Life Possible
- Dementia Education for All

Over the decade, we have incrementally grown our research capabilities, partnerships and postgraduate research community. The impetus for all our projects has been the recognition of an issue and the need for evidence-informed approaches. Early successes in funded research grants for studies in advanced dementia, and dementia and employment, laid the foundations to develop our applied research through the decade.



Dementia Palliare highlighted the importance of evidence-informed education for practitioners to improve the care of people in the advanced stages of dementia, providing the foundations for our Dementia Education for All programme of research and the impetus for changes in practitioner education across Europe.

## **DEMENTIA PALLIARE 2014 – 2016**

**Funder: Erasmus+ Key Action2 in 2014**

Concerned by reports of variation in the quality of dementia care and dementia education around the world, we focused our attention on the advanced stage of the illness, and developed the Dementia Palliare project. The aim of Dementia Palliare was to create evidence informed approaches to prepare the European workforce to provide high quality advanced dementia care. Our research challenged current conceptualisations of advanced dementia and the preoccupation with death and dying. The Dementia Palliare Best Practice Statement (BPS) set 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. To date, this research has improved the care and support of people with dementia across Europe, through innovative education and practice-based interventions.

Similarly, the dementia and employment project highlighted how understanding the experiences of individuals can help to inform policy and practice, and promote initiatives which support people living with dementia to continue employment post diagnosis. This project was one of the first to inform our Living the Best Life Possible programme of research. This research has featured as good practice by Alzheimer Europe in their influential [Dementia in Europe Yearbook](#) for 2022.



## **DEMENTIA IN THE WORKPLACE 2013–2015**

### **Alzheimer's Society funded project**

Anecdotal reports of people who had been diagnosed with younger onset dementia having negative experiences in employment inspired our dementia in the workplace research. Very little attention had been paid to those who are diagnosed with dementia whilst in employment until the Alzheimer's Society funded our influential case study research in 2013. Importantly, this research was the first to show that people with dementia can continue to work post-diagnosis with the appropriate support. Four subsequent studies have allowed us to develop a deeper understanding of the experiences and support available to people with dementia in employment. With findings from our research influencing training for trade union representatives and dementia awareness training for employers, we are delighted that our research findings are beginning to improve the experiences of those diagnosed with dementia whilst still working.

These early threads clearly resonated and are evident in our vibrant PhD student research community today. Since our first PhD student joined us in 2014, exploring the use of complementary therapy for people with advanced dementia, we have celebrated many successes, including welcoming our first international PhD student in 2019; securing funds for two externally funded PhD Studentships; and legacy funding to create the Wendy Baxter Scholarship in 2021. Currently, 11 PhD students are colleagues in our Centre. We are passionate about showcasing and celebrating our PhD students' successes, whether it's gaining ethical approval for a study, publishing their first paper as first author, or the joyful celebration that comes with graduation.

## **DEMENTIA IN SECURE SETTINGS**

### **Funder: Dunhill Medical Trust**

A newer area of research for the Centre, focuses on dementia in secure settings, and follows the same approach. Again, identifying a problem with the support for people with dementia in prison, we wanted to explore how people with a suspected or diagnosed dementia were identified, referred, and supported in prison. A grant, funded by Dunhill Medical Trust in 2021 allowed us to do that. Due to complete in 2023, the findings of this project show that there are varied and inconsistent processes for identifying, referring, diagnosing and supporting individuals within and across the prisons. These important findings will inform ongoing work to co-design an evidence-informed pathway to enable the identification, diagnosis and support for people with a suspected or diagnosed dementia in prison.

As our Centre has grown, we have continued to expand and develop our research over the years to ensure it's making a direct and meaningful impact on those living with dementia in society. Key to this is our partnership with the Scottish Dementia Working Group and National Dementia Carers Action Network. As highlighted earlier in this report, our relationship has blossomed over the decade, and members from both groups are actively involved in our research programmes. We are engaging with some excitement in our first partnership project, jointly carrying out a research project we all think is important. Listen out for more news this year.

So what have we learned from our research successes over the last decade? To value the voices of people living with dementia and their families, our students, practitioners and colleagues. Wisdom often lies there, rooted in their lived experiences. Listening closely and trying to understand their reality generates and creates new directions and ideas which have the potential for impact. Finding starting points for future development of research has been demonstrated recently in the **UWS Seedcorn Fund**. Established in 2021, led by Professor Tolson and Dr MacRae and supported by the RS MacDonald Trust, the fund aims to provide early career researchers - or those new to dementia research opportunities - to explore, model and/or test interdisciplinary ideas and interventions that would support dementia care and those living with dementia to live the best life possible. Four exciting projects have already been funded in 2022. These involve UWS research teams led by sports scientists, mental health nurses and adult nurses, developing new projects exploring issues around physical health, rural care, young onset dementia care and dementia-friendly walking football, with another funding call open this year. We are looking forward to sharing how these small 'seeds' develop into impactful research in the coming years.



# Spotlight publications

Here we provide a taste of some of our seminal and influential papers over the decade.

## ***An influential publication...***

Hanson, E., Hellström, A., Sandvide, Å., Jackson, G. A., MacRae, R., Waugh, A., ... & Tolson, D. (2019). The extended palliative phase of dementia—an integrative literature review. *Dementia*, 18(1), 108-134.

<https://doi.org/10.1177/1471301216659797>

## ***A first publication...***

Smith, M., Brown, M., Ritchie, L., Papadopoulou, C., & Tolson, D. (2022). Living with dementia in supported housing: A systematic review and thematic synthesis of qualitative research. *Health & Social Care in the Community*, 30(3), e589-e604. DOI: [10.1111/hsc.13618](https://doi.org/10.1111/hsc.13618)

## ***Publications for practice...***

*All our team worked together with students and practitioners to develop this series of publications for Nursing Older People. This series on Advanced Dementia shared our knowledge and expertise for an audience of practitioners to improve practice.*

Brown M, Tolson D (2020) Introduction to living with advanced dementia series. *Nursing Older People*. doi: 10.7748/nop.2020.e1169

Brown M, Tolson D, Ritchie L (2020) Changing needs in advanced dementia. *Nursing Older People*. doi: 10.7748/nop.2020.e1204

Jack-Waugh A, Brown M, Henderson J et al (2020) Delivering personal care for people with advanced dementia. *Nursing Older People*. doi: 10.7748/nop.2020.e1193

Brown M, Mitchell B, Quinn S et al (2020) Meaningful activity in advanced dementia. *Nursing Older People*. doi: 10.7748/nop.2020.e1171

Macrae R, Duffy FJR, Brown M et al (2020) Learning and leadership in advanced dementia care. *Nursing Older People*. doi: 10.7748/nop.2020.e1189

Sharp B, Henderson J, Brown M et al (2020) Palliative and end of life care for people with advanced dementia. *Nursing Older People*. doi: 10.7748/nop.2020.e1191

### ***Publications from our Dementia Education for all research...***

Ritchie, L., Henderson-Bone, S., Gregory, A., & Jenkins, N. (2023). Dementia education in a primary school classroom: A pedagogical perspective. *Dementia*, 14713012221149760.

Jack-Waugh, A., Ritchie, L., & MacRae, R. (2018). Assessing the educational impact of the dementia champions programme in Scotland: Implications for evaluating professional dementia education. *Nurse education today*, 71, 205-210.

Hvalič-Touzery, S., Skela-Savič, B., Macrae, R., Jack-Waugh, A., Tolson, D., Hellström, A., ... & Pesjak, K. (2018). The provision of accredited higher education on dementia in six European countries: An exploratory study. *Nurse education today*, 60, 161-169.

<https://doi.org/10.1016/j.nedt.2017.10.010>

### ***Publications from our Living the Best Life Possible research theme...***

Ritchie, L., Tolson, D., & Danson, M. (2018). Dementia in the workplace case study research: understanding the experiences of individuals, colleagues and managers. *Ageing & Society*, 38(10), 2146-2175.

<https://doi.org/10.1017/S0144686X17000563>

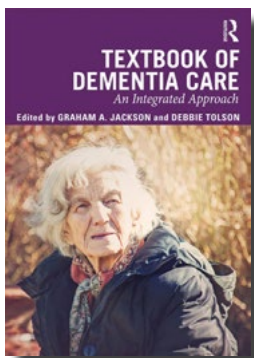
*[This seminal publication was the first to demonstrate that people living with dementia can and do continue employment post diagnosis. This paper sets the scene that with support, employment can be part of life post diagnosis and has influenced further research and training to support employees with dementia.]*

Abreu W, Tolson D, Jackson G, Costa N. (2018) A cross sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia. *Dementia*

<https://doi.org/10.1177/1471301218773842>

Coll-Planas, L., Watchman, K., Doménech, 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>



### ***A Textbook...***

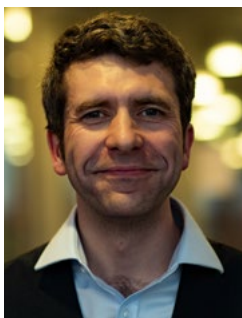
Jackson G, Tolson D (Editors) (2019) Textbook of Dementia Care: an Integrated Approach. Routledge. London, New York.

# Scottish Dementia Research Consortium: What's been happening?



The ASCPP have been long time members of and collaborators with the Scottish Dementia Research Consortium (SDRC): a community of around 1000 members including researchers and anyone else with an interest in dementia research from across the country. Interestingly, the SDRC also celebrate our 10th anniversary in 2023. A lot has changed in that time, but both organisations' commitment to supporting those living with or at risk of dementia through research has remained constant. This is clear through the invaluable contribution of Dr Louise Ritchie and Prof Debbie Tolson, who are both SDRC Executive Committee members. Debbie has been a member of the Executive Committee from the beginning and has been a continual source of knowledge and expertise throughout the past decade.

One of the most significant changes for the SDRC in the past 12 months is the appointment of Dr Terry Quinn as the new Chair. The following is a message from Terry:



*“An anniversary is always a time for looking back and reflecting. It is also an opportunity to celebrate past successes. There is no doubt in my mind that the many successes of SDRC are in no small part due to the input and support we have received from Alzheimer Scotland Centre for Policy and Practice. As the SDRC has grown in number and visibility, the Centre has had a fundamental role in our ‘Living with Dementia’ theme.*



*An anniversary can also be a time for looking ahead. Dementia research in Scotland is at an exciting but challenging time. The optimist in me is encouraged by the increasing recognition of the importance of dementia research by funders and government. However, the pessimist in me can't help but see the increasing strain that health and social care services face, and the direct and indirect impact that this has on dementia research. In turbulent times, academics, clinicians and third sector all need to work together. This is the approach that SDRC and the Alzheimer Scotland Centre for Policy and Practice have always taken.”*

# How to **study with us**

There are a number of opportunities to join us in the Alzheimer Scotland Centre for Policy and Practice. Our educational offerings range from research degrees through to masterclasses and bespoke CPD aligned to the skilled and enhanced levels of the Scottish Government's Promoting Excellence Framework.

## **MSc in Dementia Care**

[www.uws.ac.uk/study/postgraduate/postgraduate-course-search/dementia-care/](http://www.uws.ac.uk/study/postgraduate/postgraduate-course-search/dementia-care/)

## **Research Degrees (PhD, MPhil, MRes)**

contact [rhoda.macrae@uws.ac.uk](mailto:rhoda.macrae@uws.ac.uk) or

[www.uws.ac.uk/research/doctoral-college/](http://www.uws.ac.uk/research/doctoral-college/)

## **Professional Development**

<https://cpd.uws.ac.uk/w/courses/cat-39-wellbeing/>





# How you can **get involved in our work**

**If you're inspired by our work, there are several ways you can help us achieve more.**



Donate now. You can provide vital help with a donation to support a student scholarship, fund research, provide equipment or help us expand our service faster. To discuss this with no obligation, please contact Nicola Smith, Director of Fundraising & Alumni, UWS by email at [nicola.smith@uws.ac.uk](mailto:nicola.smith@uws.ac.uk) or by phone on **0141 848 3084**.

Join us as a “critical friend” to help influence our research agenda, 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.

Volunteer with Alzheimer Scotland to offer practical support to people living with Alzheimer's and dementia. You can find out more and register your interest at [www.alzscot.org/volunteer-with-us](http://www.alzscot.org/volunteer-with-us)

For further information, please contact:  
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**Alzheimer  
Scotland**  
Action on Dementia



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Dementia Helpline**

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you 24/7**

**alzscot.org**



**Alzheimer  
Scotland**  
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