



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

Our collaborators



























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At UWS, we are committed to making a global impact and we believe in excellent, relevant and purposeful research.

The Alzheimer Scotland Centre for Policy and Practice embodies these values and continues to blaze a trail in dementia education.



This year, I want to again pay tribute to the continued commitment of my colleagues in the (entre and our partners. They have risen to the unique circumstances created by the pandemic and continue to deliver on their objectives.

Our dementia education and applied research is world leading and impacts on the lives of many. UWS is a significant force in global knowledge creation, innovation and a leading provider of higher education. Our team are transforming lives and making an impact on how the world sees and responds to this public health priority through applied research and enhancing the knowledge of practitioners and carers of those with dementia through, workforce development, upskilling leadership programmes and our dementia degrees.

Last year, we were delighted to celebrate the work of many of the practitioners who went above and beyond in the early stages of the COVID-19 pandemic. This year, I want to again pay tribute to the continued commitment of my colleagues in the Centre and our partners. They have risen to the unique circumstances created by the pandemic and continue to deliver on their objectives.

This year, the report, as well as highlighting all of the outstanding work of the Centre throughout the year, dedicates a focus to our signature Care Empathia approach. One of our UWS commitments is to be both creative and challenging in our pedagogy. Care Empathia is a leading example of how we do this in practice. In a rapidly changing world, signature approaches ensure that no matter how education is delivered, be this online, face-to-face or through hybrid approaches, and wherever our students are in the world, the UWS learning experience is transformative. I am confident in saying that our dementia education is a leading example of this approach to learning.

Professor Craig Mahoney,

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

2021 in numbers



19 Journal articles published

5 Book chapters

1 Edited book



7 Enterprise contracts



18 Conference presentations



1 REF21 Impact Case Study



1 Emergency Services Pledge



22 MSc students

8 PhD students

100+ Digital Dementia Champions Programme Participants

161 CPD Course attendees



Welcome to our 2021 Annual Report. This year we are celebrating excellence in dementia education. With a feature article on our signature pedagogy Care Empathia, this is our award winning approach to dementia education. At UWS we believe that higher education is about changing the world and making it a better place through the actions and leadership of our students. At ASCPP our students include pre and post registration practitioners, care home staff, family carers and volunteers to name but a few. We are also sharing good news from ASCPP researchers and affiliates.

In partnership with Alzheimer Scotland we are delighted to be leading on the delivery of the new Dementia Champions 2021, Scottish Government funded workforce development programme for over 150 aspiring Dementia Champions. Later in the report you can read about this new online programme and see how the Alzheimer Scotland Dementia Nurses and AHP Consultants are working with us. I warmly thank all members of the Dementia Champions Faculty and the people with dementia and family carers from SDWG, NDCAN and TIDE who bring the voice of lived experience to the Dementia Champions learning experience.

As featured on the front page of The Herald in April, we have been honoured and humbled to receive a legacy donation from the Baxter Family to remember the amazing contribution of the late Dr Wendy Baxter. Dr Wendy Baxter was a palliative care consultant who promoted dementia palliation long before it was talked about in the literature. The opportunity afforded through the Wendy Baxter Scholarship sees us welcome our new Wendy Baxter Scholar, as well as two new doctoral research students supported through UWS studentships. Read more about our new and continuing research students in the 'Meet our students' section of this report.

Although pandemic delays to research funding awards have been a little unnerving, we are absolutely delighted for Dr Louise Ritchie and her team, who have received a major Alzheimer Society project grant. A wonderful new project that was launched in October, focussed on developing career guidance approaches to support those who are diagnosed with

dementia whilst in employment. Our new research fellow Dr Laura Lebec joins the team and will support the development of this project. We look forward to providing updates in the coming years!

With thanks to the Dunhill Medical Trust, for their generous funding to support dementia in prison research. Dr Rhoda Macrae and new research fellow Dr Natalie Chalmers are leading an interdisciplinary research team. Although it is still early days for this new project a huge thank you to all in the Scottish Prison Service and NHS Prison Healthcare teams who are collaborating with us and recognise the importance of dementia care pathways for all.

We have been encouraged by the impact of trauma informed approaches within dementia education. We applaud Dr Eileen Harkess-Murphy and team for success in securing monies from the Scottish Neurological Research Fund to commence research examining Helpline Calls through a trauma informed lens. This research will strengthen the evidence base for telephone helpline practice, a service that has been in much demand during the pandemic.

Over the coming two years we aim to grow the number of UWS early career researchers and researchers new to dementia care research to pioneer new ways to support people to live the best life possible with dementia. We can do this thanks to RS Macdonald Charitable Trust for their generous Seedcorn Funding.

As you can see the team have adapted to remote working, and kept themselves busy during a turbulent year of lockdowns. We hope to be back on campus soon and thank everyone who has remained involved in our education and research. The generosity and commitment of many, who share their lived experiences, dementia practice know how and others who work with us behind the scenes are essential to our collective ASCPP successes.

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

Endorsements

Chief Executive, Alzheimer Scotland



Excellence in applied research is critical if we are to transform the lives of people living with dementia and carers of people with dementia. It provides the evidence for shaping policy and practice, so that we can continually strive to transform their lives throughout the illness and in any setting. This past two years of living through a global pandemic has been devastating for many people with dementia, their families and carers and has exposed the gaps between the aspirations of national dementia policy and people's lives. This challenging time has demonstrated even more the need for the highest quality of evidence informed practice and education as delivered by the Alzheimer Scotland Centre for Policy and Practice.

Alzheimer Scotland is delighted to work in partnership with a team so committed to changing lives by championing excellence in advancing dementia policy and practice through education. The importance of attracting and training talented and passionate individuals to be the next cohort of dementia practitioners cannot be overstated. I was therefore delighted that the Centre was awarded a new contract from NHS Scotland to continue the Dementia Champions programme. Having been associated with the programme since its earliest days, Alzheimer Scotland welcomes the development of this award-winning programme for digital delivery and the curriculum's emphasis on the lived experiences of people with dementia during the COVID-19 pandemic.

In addition, we are deeply indebted to the family of the late Wendy Baxter for the donation allowing for a legacy scholarship to be established in her honour. There is no doubt that Wendy's involvement in the dementia and palliative care fields impacted on the lives of many thousands of people, and I cannot think of a better tribute to her memory.

The Centre continues to be a driving force in motivating positive practice with its signature method 'Care Empathia', structuring teachings on the three strands think about, feel about and what they do about dementia. The inclusion of trauma-informed as a response to the pandemic is a vital addition as people living with dementia and their families have been significantly impacted by COVID-19 and the disruption to their usual support services.

The Centre has adapted and innovated remarkably in response to the pandemic, and we congratulate the Centre for continuing to progress ground-breaking research and securing funding for future projects during this time.

Henry Simmons



National Dementia Carers Action Network (NDCAN)

The National Dementia Carers Action Network (NDCAN) has been delighted to have worked with colleagues at the Alzheimer Scotland Centre for Policy and Practice over the past year. Despite the challenges that COVID-19 has presented, NDCAN has continued to work alongside the ASCPP on projects such as their research involvement group, which was formed as a collaboration between NDCAN members and the Alzheimer Scotland Centre for Policy and Practice. This group gave NDCAN members the opportunity to consider what they wanted to achieve through contributing to research and resulted in them becoming researchers themselves and developing their own research projects. NDCAN also continued to support the valuable work being done by the ASCPP on projects such as the Carer's Academy and the Dementia Champions programme. Congratulations to the Centre on another successful year of work.



The Scottish Dementia Working Group (SDWG)

The Scottish Dementia Working Group (SDWG) would like to congratulate the Alzheimer Scotland Centre for Policy and Practice (ASCPP) on another year of such vital and important work. Over the years, SDWG members have worked closely with colleagues at the Centre on projects such as the Dementia Champions programme. SDWG members value the improvement that the programme has made to people with dementia in a hospital setting, and over the years they have appreciated the opportunity to share their lived experiences with healthcare professionals. It is paramount that the voices of people with dementia are heard in this way. There have been so many challenges over this past year for people with dementia, but despite this, SDWG members have continued to campaign and raise awareness, and we look forward to continuing to work with our colleagues at the ASCPP in the future.

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 facility. 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 Gerontology with Dementia Care), and independent research degrees - MRes, MPhil and PhDs.

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



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. She leads the Living with Dementia Research Theme as an Executive Member of the Scottish Dementia Research Consortium.



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 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...



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.



Dr Eileen Harkess-Murphy

Eileen is a psychologist who has expertise working in practice and research within the area of health improvement, mental health, and wellbeing. Eileen has an interest in psychological trauma and how trauma-informed approaches can mitigate risk of re-traumatisation for carers and people with dementia. Eileen is currently leading a multi-centre research 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. Eileen has expertise in medical statistics and data analysis, she teaches on the BA (Hons) Integrated Health and Social Care programme and supervises several postgraduate students.



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.



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.



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 Palliare partner and currently supporting International Student Networking Conversations.



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.



Dr Anna Jack-Waugh, SENIOR 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.



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.



Dr Rhoda MacRae, SENIOR LECTURER

Rhoda takes a lead role in enterprise and research activities within the Centre. Her research interests include dementia in secure settings and dementia education. She is currently leading a research study into referral, diagnostic and post diagnostic care pathways for people living with dementia in prison and an Institutional Seedcorn Fund designed to support early career researchers and those new to dementia research to undertake applied dementia care research. She teaches on two masters programmes, CPD programmes and is the divisional coordinator for the postgraduate research students.



Dr Louise Ritchie, READER

Louise is a Reader 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.

Our **Associates**

- · Jayne Brinkworth, National Active Voice Lead, Alzheimer Scotland
- · Joyce Gray, Deputy Director for Development, Alzheimer Scotland
- Jenn Hall, Head of National Support Services, Alzheimer Scotland
- Dr Nick Jenkins, Senior Lecturer, University of the West of Scotland
- · Alison McKean, Allied Health Professions Post Diagnostic Lead, Alzheimer Scotland
- Dr Bryan Mitchell, Lecturer, University of the West of Scotland
- Jim Pearson, Director of Policy and Practice, Alzheimer Scotland
- Dr Shelley Peacock, Associate Professor, University of Saskatchewan
- Professor Elsa Sanatombie, Manipal Academy of Higher Education, India
- Dr Barbara Sharp. Independent Consultant.
- · Henry Simmons, Chief Executive, Alzheimer Scotland
- Kirsty Stewart, Executive Lead Stakeholder Engagement, Alzheimer Scotland
- Marri Welsh, Head of Communications and Campaigns, Alzheimer Scotland
- Dr Stuart Wood MBE, Independent Music and Health Researcher



Meet our newest Doctoral students

Wendy Baxter Scholarship at ASCPP

The scholarship has been made possible thanks to funding from the family of the late Dr Wendy Baxter M.B.E, who throughout her career was dedicated to improving palliative and dementia care.

Diagnosed with dementia herself in 2017, Wendy spent her final months – including three during the Covid-19 lockdown – as a care home resident with dementia. Through this legacy scholarship, Wendy's commitment to palliative-informed and evidence-based dementia care will live on.

Caring for a relative with dementia involves both rewards and strains, and adapting to the realities of this progressive condition, including adjusting to care home admission. The research that will be undertaken through this PhD scholarship will explore and develop approaches to supporting positive practices to support families and care home residents to spend quality time together.

Congratulations to Connor Macdonald who has joined ASCPP as the Wendy Baxter Scholar.



Connor Macdonald, Wendy Baxter Scholar

In 2015, I started my undergraduate degree in Society, Politics and Policy at University of the West of Scotland which was a fascinating course which instilled a drive to pursue a career in Social Policy which has remained to this day. Following this, I graduated with a Masters in Social Policy from the University from Strathclyde which strengthened my desire to work in a policy related job. As part of both my degrees, I completed two dissertations which focussed on different dementia related policies and how they help those living with dementia and their loved ones, with my Honours project looking at the post diagnosis support for younger people with dementia and my Master's examining the experiences of those with dementia in the workplace. I am excited to take up the Wendy Baxter Scholarship and work as part of the ASCPP, as they are at the forefront of dementia research in Scotland and as a result can help to drive policy direction. My immediate priorities are to get to grips with what is currently happening and what is already known about the experiences of family carers of someone with advanced dementia. During my first year this will involve preparing a literature review and speaking with family carers and other stakeholders in order to fully understand their experiences and how we can improve them.



Rachel Allen

I am so happy to be joining the research team at UWS and ASCPP. I am grateful for funding through a UWS Studentship for my PhD, which will explore career development for people with early onset dementia. The supervisory team for my PhD is Dr. Louise Ritchie (Lead Supervisor) Dr. Emma Bolger and Professor Debbie Tolson. I find the connections between identity, work and disability fascinating, and a priority for my research will be ensuring positive outcomes that can have impact and truly make a difference. We currently know so little about early onset dementia in relation to continuing work, and how working may need to be adapted or redefined when symptoms of dementia progress. It is exciting to be a part of changing this and contributing to ASCPP's outcomes for those living with dementia. I have focused on starting well and finding my feet for the journey ahead, and I look forward to providing further updates as my project progresses.



Kate Lynch

I am delighted to commence my full-time PhD studentship at University of the West of Scotland this month and look forward to working collaboratively within the Alzheimer's Scotland Centre for Policy and Practice. My background is within health psychology and biomedical science. My project will focus on developing an integrated pathway to improve the care of people living with a dual dementia-cancer diagnosis.

There exists a growing number of individuals living with cancer and dementia and navigating hospital cancer care, and accessing appropriate support individual to their needs is vital.

Over the coming months I aim to conduct a systematic literature review of the care experiences of people living with dementia and cancer and to develop my research methodology and design. The project aims to incorporate the views and experiences of people living with dementia-cancer, their carers and health professionals working in cancer care. I look forward to engaging with the skilled networks of professionals working within this area, to enhance accessibility and equality in cancer care for people with dementia and cancer in Scotland.

Doctoral progress and achievements

Congratulations to Michael Smith, Angela Gregory and Mohammad Mollah who have successfully completed Transfer Events. This means they are doing great at the halfway stage...



Michael Smith

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

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 has since been accepted for publication in the journal of Health and Social Care in the Community, and I will also present the findings of this work at the Alzheimer Europe Conference in December 2021.

In September 2021, I received ethical approval to conduct the next phase of my research study. The aim of this stage of the research is to develop an in-depth understanding of the experience of living with dementia in supported housing, using an exploratory, multiple-case study research design. I hope to complete data collection for this stage by June 2022.



Angela Gregory

Angela has a background as a freelance artist, a singer and is an occupational therapist. She started her PhD in August 2019, funded by UWS, Erskine and Alzheimer Scotland, with additional funding from the Scottish Dementia Research Consortium.

Angela's research aims to understand the concept of meaning in activities and interactions with people living with advanced dementia in a care home setting. Using Participatory Action Research, Angela will work with people living with advanced dementia, their family members/friends and care home staff using creative methods. Angela recently presented her work as part of a symposium for the British Society of Gerontology conference 2021, discussing creative methods in dementia research.

Angela received ethical approval from Scotland A Research Ethics Committee in September 2021. Owing to COVID-19, Angela has received an extra six months' funding from the University and is due to complete in February 2023.



Mohammad Mollah

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.

I have completed an integrative literature review and prepared the draft of the thesis chapter that aimed to critically review the development and implementation of dementia care strategies in Scotland and Bangladesh. I have prepared a draft Documentary Policy Analysis to understand the dementia policy landscape and developments in Scotland. I have secured Ethics Approval in November 2020 and have completed data collection from the key policy stakeholders in Scotland and the Nominal Group Discussions with stakeholders in Bangladesh. I have presented my study design at the HEDN meeting in May 2021. I have also presented a paper on the experiences of dementia in Bangladesh in the Global Symposium Series in September 2021.



Yvonne Manson

I am a part-time research student who works full time as the Care and Dementia Services Director at Abbotsford Care covering eight Care homes in Fife. I have just finished my first year, where as well as getting to grips with constructivist grounded theory, I was also awarded the Queen's nurse title. Commencing a PhD while working frontline in a pandemic has brought its own challenges. Having worked collaboratively with people with dementia and their families in care homes throughout my 26-year career I am excited to have the opportunity to now be exploring the experiences and understanding of partnerships in practice in care homes as a researcher. I feel very fortunate to be fully funded by Abbotsford Care and to be on this journey.



Carol Beckwith

With a background in psychology, music and song writing, Carol enrolled as a part-time PhD student in October 2020. My research aims to explore how song writing practice can be applied in such a way that it gives insight into difficult to articulate experience.

The focus is on the lived experience of Young Onset Dementia Carers, and in how they can be supported, through collaborative song writing practice, to explore and make tangible, the very particular complexities that Young Onset Carers face. The research will take place in informal, community settings; places where carers already go with their loved ones, to find support and where they can take part in song writing workshops while their loved ones are cared for by staff and volunteers.

"Having started during the 2020 lockdown, I am very much looking forward to spending some time on campus this academic year and getting to know the staff and students in the Centre."

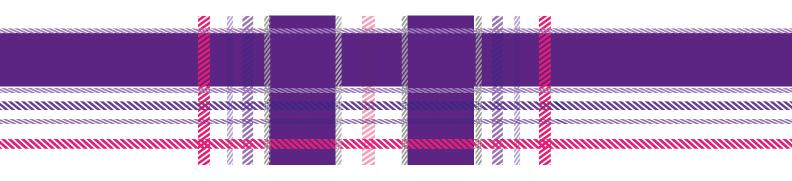
Teaching the workforce of the future

The ASCPP team teach into a range of undergraduate and postgraduate programmes. These include the undergraduate adult and mental health nursing programmes, the BA in Integrated Health and Social Care, the MSc in Leading Peoplecentred Integrated Care and our own MSc Gerontology (with Dementia Care) which you can find out more about at

www.uws.ac.uk/study/postgraduate/postgraduate-course-search/gerontology-with-dementia-care/

The Health Education Academy's (2011) UK Professional Standards Framework for Teaching and Learning in Higher Education, coupled with the practice ideals enshrined in the Promoting Excellence Framework and the Dementia Training Standards Framework guide all our work. Integrated multidisciplinary practice is not just what we teach, it is how we practice as we apply contemporary research to shape our education provision. We also use our educational experiences to inform the direction of our research. The synergy between education and research is the key to our quality and our impact.

We encourage all of our students to be leaders of change, to be intolerant of poor standards and so challenge the status quo. Our starting point for planning learning activities has always been an evidence-based understanding of the varied experiences and perceptions people have of dementia combined with a spirit of creative inquiry.



MEET GERALDINE, ONE OF OUR MSc STUDENTS

Our MSc students are all practitioners from different disciplines who strive on a daily basis to provide excellent dementia care in various care settings. This year we spotlight Geraldine Hutton, MSc in Gerontology (with Dementia Care) student.



Geraldine Hutton leads a team of Older Peoples' Mental Health Acute liaison nurses within NHS Greater Glasgow and Clyde and previously worked as Mental Health Practice Development Nurse. In 2016, while studying with us Geraldine and her practice development colleagues won a Mental Health Nursing Forum Award for setting out a strategic approach to carrying out patient well-being focused improvement projects within specialist dementia wards looking at physical health and assessment.

Discussing participation in the MSc programme, Geraldine stated that through the programme she had obtained up-to-date best evidence across a range of subject matters, and developed critical thinking skills, which provided her with the confidence to question and critique practice situations. This related not just to patient care issues but also to leadership, strategies, health care initiatives, quality improvement and audit.

She said.

I feel the MSc helped me to build a more robust approach to my professional practice, pulling together real life, the ideal, and 'what if?' scenarios. I also found the other participants in this course to be like-minded, and benefitted from the diversity of their professional backgrounds, opinions and experiences which added significantly to my personal learning.

We wish Geraldine best wishes in whatever comes next and hope she will continue to share her learning with her colleagues to ensure quality of care for all the people living with dementia, which they encounter.

Care Empathía

Our educational signature



Introduction

We have a 'way of working' that permeates our learning and teaching about dementia; you could say this is our signature educational approach. We call this *Care Empathía*, learning through knowledge (the head), feeling (the heart) and doing (the hand).

Care Empathía is an organising principle, forming the foundation of our learning and teaching from short sessions to degree programmes. It influences what we teach, how we teach, and what is learned. This strong foundation creates the conditions to deepen understanding, connection, practical actions and solutions. A learner will leave the briefest session with something they can do immediately to make a difference.

Care Empathía is rooted in values and human rights and shared with our partners in Alzheimer Scotland. In the early days of our partnership, we recognised kindred spirits in one another. The more we talked and taught together, the more we realised that we did something special. Our successful joint learning programmes created strong emotions, (laughter and tears), knowledge and deep practice change. Conversations about what we do, culminated in naming what we do: Care Empathia.

What is Care Empathía?

Care Empathía is about creating a compassionate and safe learning space, to share prior knowledge and lived experiences, building confidence and creativity in practice-based learning. We do not shy away from the need for knowledge of the neuropathology and physical impacts that make dementia so complex. Instead, this is wrapped around in a person-centred and compassionate understanding of the dementia lived experience. We create the possibility that the right kind of care can reduce the impact of brain changes in daily life. For the practitioner it also involves equipping them with practical and sensitive haptic or psychomotor skills.

Care Empathía has been emerging for over ten years through a creative interplay among academics and practitioners' knowledge and experience and the lived experience of people affected by dementia. Grounded in authentic dementia education practice, we have deepened understanding of effective practice learning through research including, the European Palliare project* and Scotland's Dementia Champions*.

This head, heart and hand is not a new principle in learning theories. Bloom* believes that we learn best when three domains are activated, the head (cognition), the heart (affect) and the hand (action). More recently, Sipos* has developed the head, heart and hand principle to transform learning about sustainability in worldwide ecology systems. We were already sold on sustainability, transformative learning and the best possible learning experience, now it was time to apply this to dementia care and our own values as *Care Empathía*.

The Care Empathia learning experience

Learning happens everywhere but enriched in creative spaces and places. Being in person with learners, led us in 2011 to develop a learning space called the Domus, meaning 'home' in Latin.







This highly adapted space moved learning into the world of the person with dementia. We invite learners to see the space as a care agent, understanding the impact and potential for an important and frequently invisible element in the delivery of care. Here we can practise care skills safely, including the fundamentals of eating, drinking, dressing and grooming. The homelike space maximises independence and supports the best life possible. Understanding the meaning of home, simulated experiences and role-play refine and apply knowledge to real life.

Expanding this space into our simulated hospital wards created opportunities, to move outside our room and include different care spaces - showing simple changes that make a difference. Here changing the colour of bedlinen to reduce fall risk, as the person can see where to sit.



We use ways of engaging that include safety and gentle disruption, providing simulation and role-play activities with humour and the universal trauma precautions of safety, choice, collaboration, trustworthiness, and empowerment. We use *Care Empathía* to create the very best conditions for learners to reimagine the head, heart and hand of the dementia experience and the best possible ways to care.

Teaching Care Empathía

Let us look closer at our three ingredients of the head, heart, and hand for learning in turn.



The Head



The head ingredient brings knowledge of the changes in the brain, which result from dementia. This is crucial to appreciate many of the sensory and functional difficulties experienced by the person. However, this is insufficient to comprehend what it may be like to live with a diagnosis of dementia and how this creates challenges in providing the fundamentals of care and support. During a *Care Empathia* learning experience, old perspectives are exchanged for new ways of thinking, including self-perception and relationships with others. Bringing neuropathological changes to practical applications creates a new understanding of people and their responses, behaviours and experiences. This helps learners to appreciate how this is part of the complexity of the person's experience and can be altered, perhaps more than they imagine, by attention to other influences. Something can always be done to make a difference.



The Heart



The second ingredient is the heart. Knowledge without values and affective understanding is not enough. We need to develop a deeper compassion and a value base, reflected in every contact with other people. Content includes role-play based vignettes and the involvement of people with dementia, family carers and friends in the development and engagement with learning experiences. We use creative and positive methods, including art, poetry, music and film, to learn about the experience of people living with dementia, their families and friends. Role-play and modelling develop and enhance high levels of skilled communication and interaction.



Experiential simulation is one way of developing deeper understanding of the person who may not have the verbal language to express choice. Learners, after clear preparation and discussion about physical and psychological safety, engage in risk assessed, simulated everyday care experiences. We offer a range of equipment to create multiple sensory and age-related changes to vision, hearing and mobility. Learners can choose to engage, simply observe or opt out completely. Having a choice is $Care\ Empathia$, together with the opportunity to reflect and learn from these choices. These reflective experiences are core activities, so following these experiential simulations there are periods of intensive structured reflection, individually and then in small, facilitated groups.



We can laugh too!











We will let the learners tell you more about this...

- I was thinking about people that I was looking after who had difficulties around meal times...and thinking about what the problem could be for them and what solutions we could offer in our environment.
- Gave me an appreciation of how difficult life can be in hospital with dementia when you require physical help with activities of everyday living.
- 66 Practical learning I can take back to my ward to make a difference.
- 66 I think what I learnt will stay with me for a long time. 99

Bringing it together

Essential to *Care Empathía* is bringing together the head, heart, and hand of the learner, developing with them the best possible approach to care for the person living with dementia. The approach integrates practical and practice-based activities, skill development and knowledge, using continual reflection to maximise learning while enhancing emotional and cognitive understanding, and revisiting a range of psychomotor skills to create care solutions with learners.

The approach uses learning that considers the experiences that learners bring into the learning environment. Personal and group learning intensifies by sharing and exploring experiences. While recognising the valuable knowledge and understanding others bring to the group, it is enriched by time to consider and reflect on theoretical and research-based findings.

An exchange of ideas, theories and innovations emerge from the equal relationship structure developed during the learning experience. The approach and attitude of teaching staff is knowledgeable and respectful of current practice creating a learning partnership.

Care Empathía can be found here

Care Empathía principles support our national contribution to learning about dementia in Scotland's Dementia Champions and our complex needs sessions for the Dementia Specialist Improvement Leads programmes. It permeates all our short learning programmes from care homes, the NHS, HNS Education for Scotland and Alzheimer Scotland. The new Discover Dementia thread in the pre-registration programmes for nursing and paramedic science reflect the Care Empathía signature. Our award-winning venture, our Centre Carers' Academy, brings Care Empathía to family carers who learn at our university campus sites in Ayr and Lanarkshire. Our award-winning Class in a Bag learning packs even touch the lives of children, and Care Empathía continues in Molly's Story.

We have taken *Care Empathía* beyond our shores to other countries, pre pandemic. Delivering a summer course in the University of Alicante, Spain, we learned that empathia in Spanish means empathy, so we know language is on our side too.

The Care Empathía vision



Our image of Care Empathia is inclusive, loving, and relational, comforting, and caring, because we believe learning should engender such reactions. We decided to commission an image that reflected this.

Mrs Marjory McCallum (artist).

Final thoughts from the Team

Human rights and values must underpin learning about people. Care Empathia makes a difference..."I know about dementia, I value and care about what you might be experiencing and I have actions I can take that will make a difference".

Care Empathia is like a golden thread that runs through our Centre, built and shared through the partnership with Alzheimer Scotland and increasingly with others commissioning learning programmes. The team wanted to share this with you, so you know that when you learn with us you will intensify, how you know, how you care and how you act. We want you to take our signature educational principle of Care Empathia with you.

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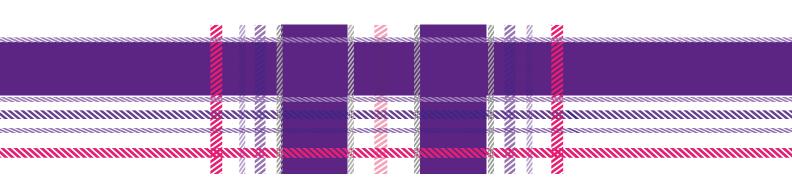
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Tolson D, Holmerova I, Macrae R, Waugh A, Hvalic-Touzery S, de Abreu W, Lillo Crespo M, Merta A, Hanson E. (2017) lmproving Advanced Dementia Care an Interprofessional Learning Framework JAMDA http://dx.doi.org/10.1016/j.jamda.2017.03.014.

Research Propelled Teaching: Discover Dementia, Discover Research

Dementia education within Mental Health Nursing, Adult Nursing and the Paramedic Science programmes are directly informed by ASCPP research. Innovations in dementia education began with introducing the Dementia Spiral, which threaded dementia throughout undergraduate nursing and mental health programmes. This approach has been revitalised for current nursing and paramedic science programmes, where students, throughout their programmes, benefit from a bespoke series of learning units called Discover Dementia.

More recently, we have led the creation and piloting of a Discover Dementia eResource to support students on any programme to learn more about dementia and learn from staff and research students involved in dementia research at UWS. The bespoke learning units are mapped to the Promoting Excellence Framework 2021. In addition, live and recorded seminars allow students to discuss research-informed practice and current research projects with ASCPP dementia experts.



Beyond CATE



In 2020 we were delighted that our teaching excellence was rewarded by Advance HE with a CATE (Collaborative Award for Teaching Excellence). Class in a Bag: Understanding Dementia is certainly something to shout about. It offers state-of-the-art experienced based learning for our nursing students. Plus, it supports local schools in delivering health promotion for children, and for society. Together we are creating a new generation of dementia positive young people.

Although COVID took the shine off of our celebrations, we were delighted to be selected to contribute a chapter in the first Edition of The CATE Collection: Together in Collaborative Educational Leadership published by Advance HE, UK. Naturally our outstanding former colleague Winnie McGarry led the team in writing our chapter. We can't believe that Winnie retired before seeing this in print! How we miss Winnie's professionalism, expertise and elegance. An exceptional role model for student nurses and an innovative nurse educator. A huge thank you to Winnie and outstanding colleagues Wendy Wright, Caroline MacCallum and Fiona Everett from the Adult Nursing education team, ASCPP colleagues and students who continue the CIAB journey.

Winnie's commitment to raising awareness of dementia and facilitating insight that could make a positive difference really shone through and made a lasting impact. I myself employed the hand over hand method that Winnie patiently instilled to provide respectful care which promoted nutritional intake. I remember a particular occasion when an older patient looked at me with gratitude and said 'thank you, for understanding that I find this really difficult, and for taking the time to help me to do it for myself'. It was a very moving experience which highlighted the importance of understanding dementia and promoting dignity, respect and independence.

Arlene Allison, BSc Adult Nursing graduate

Winnie has excellent leadership skills to promote and educate the innovative (IAB. Her enthusiasm and inspiration brought her colleagues and nursing students to be involved and inspired with (IAB. Thank you to Winnie! She has inspired me to go into health education and promotion!

Karen Ross, BSc Adult Nursing graduate

We are indebted to Winnie for her professionalism and leadership in taking the lead on the (ATE submission and for her excellent skills in keeping everyone up to date and involved.

CATE Team

Winnie has continually demonstrated her knowledge and passion throughout the (ATE submission process but also driving Dementia: (lass in a Bag from the initial thoughts to this now being a part of the Adult student nurse curriculum. There are many thousands of children who have been given an insight to dementia through Winnie's enthusiasm and drive.

Wendy Wright and Caroline MacCallum, UWS Adult Nursing lecturers

Class in a Bag Research

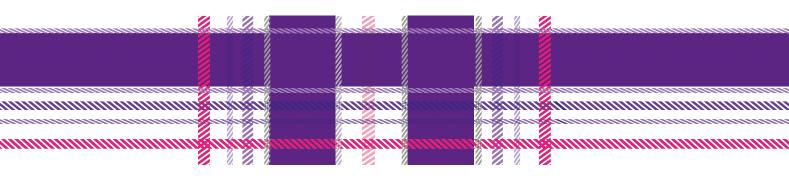
An important part of this journey includes our CIAB interdisciplinary research which aims to understand how children learn about dementia, and how the materials in class in a bag can facilitate this. Our research, which was funded through the UWS Crucible programme, allowed us to collaborate with colleagues Dr Susan Henderson and Dr Nick Jenkins from the School of Education and Social Sciences to provide an innovative insight into children's experiences of using the Class in a Bag resource. We provided the children with iPads to allow them to film their learning experiences as they engaged in the activities in the Bag. The research has provided an insight into the process of learning about dementia, as well as how the children understand dementia. The findings show that children interact with the objects in the bag in a variety of ways, helping them understand the experience of dementia, brain health and how to help a person with dementia. This research has helped provide the foundations for future pedagogical research in this area, as well as allowing us to make recommendations for future educational initiatives.

Scotland's National Dementia Champions 2021 Digital Delivery

In early March of 2020, members of the Alzheimer Scotland Centre for Policy and Practice attended the graduation of 100 Dementia Champions in Edinburgh. Although joyous, the event was permeated with concern about how Covid-19 would affect everyone. Two weeks later, Scotland went into lockdown and there were some uncertainties for what would happen next in terms of dementia workforce development.

We are delighted that as part of the Scottish Government, Dementia and COVID-19: action plan Dementia Champions Programme is up and running again. The ASCPP team were commissioned by the Scottish Government and NHS Education Scotland to provide the first online version of Dementia Champions with places for up to 150 frontline practitioners. We are delivering this in partnership with Alzheimer Scotland, the NHS Alzheimer Scotland Dementia Nurse and Allied Health Professional Consultants and evaluating with the University of Dundee.

Underpinned by the pedagogical model of the previous programmes, Dementia Champions engage in six online learning units and seminars. New material includes understanding the impact of COVID-19. To enhance the experienced based nature of the programme, bespoke films have been made with a range of stakeholders, including The Scottish Dementia Working Group, National Dementia Carers Action Network, Alzheimer Scotland and The Alliance. These films ensure that the authentic voice of people with dementia and their families are central to the learning experience. To graduate as a Dementia Champion, practitioners must be able to demonstrate how they will achieve dementia positive practice changes where they work to the benefit of people affected by dementia.



Emergency Services Dementia Pledge Commitment



On World Alzheimer's Day (21 September), Scotland's emergency services reaffirmed their commitment to the national Dementia Pledge, with support from UWS's Alzheimer Scotland Centre for Policy and Practice.

Built on four key commitments, including ensuring staff have the tools and awareness to recognise and help people living with dementia, it also encourages organisations to be dementia-friendly employers by providing support to staff who are carers.

The Dementia Pledge was first co-signed by Police Scotland, the Scottish Ambulance Service, and the Scottish Fire & Rescue Service in 2019, with the support of the Alzheimer Scotland and the Centre for Policy & Practice at University of the West of Scotland.

Chief Superintendent Linda Jones, Police Scotland, said:

What's happening at home can have a significant impact on a person's wellbeing at work. As a dementia-friendly employer, we offer a range of wellbeing support to our officers and staff — as well as their families — which is underlined by our re-signing of the pledge this year.

"We are engaged in a significant range of partnership working to create dementia—friendly communities, and to ensure our officers and staff are aware how to respond to vulnerable people they encounter in the course of their duties. Our national implementation of the Herbert Protocol further strengthens our commitment to building safer communities.

Scottish Fire and Rescue Service Chief Officer Martin Blunden said:

This is an important opportunity for us and our partners to underline our ongoing commitment to support those who are living with dementia. Our staff are involved with initiatives right across Scotland and are equipped with the required skills and knowledge to help people with dementia to live safely and feel recognised and valued.

It is important that we do everything within our power to keep reaching out and support any effort to help make communities safer. That is why we launched our Make the (all campaign, and I will once again urge members of the public to contact us if they know someone who needs our support to stay safe from fire within the home. We can provide advice, tailored to an individual's circumstances, as well as direct carers and families to other partners and agencies who can assist with dementia—related support.

Scottish Ambulance Service Medical Director Jim Ward said:

We are committed to ensuring that our staff have the knowledge and skills to recognise and support people living with dementia and treat them and their families with compassion.

I'm delighted to reaffirm our commitment to the Dementia Pledge, ensuring a dementia-friendly service is delivered to communities across Scotland to help improve the safety and wellbeing of people living with dementia, their families and carers.

Alzheimer Scotland Purple Alert is an app designed to help find missing people with dementia. If someone is missing, uses are notified via the app and can assist with local searches.

Alzheimer Scotland Deputy Director Joyce Gray said:

Alzheimer Scotland is so grateful for the renewed commitment from our partners. Purple Alert can only become more successful if our community of users increases, making it more likely that someone is found safe and well. The support you give us through this renewed pledge and the day-to-day support of your teams and officers just makes Scotland a safer place for people living with dementia.

Professor Debbie Tolson, Director of the Alzheimer Scotland Centre for Policy and Practice at University of the West of Scotland said:

I am so proud to see our partners from Alzheimer Scotland, together with the emergency services, come together on World Alzheimer's Day, to reinforce their commitment to those living with dementia in signing the dementia pledge.

Almost every family in Scotland will know someone living with the illness. This pledge is significant in helping us create an understanding, dementia—friendly society across the various service areas people with dementia and their family's access to ensure they feel effectively supported and recognised. Once again, the pledge highlights a collective commitment to equip first responders with appropriate knowledge and skills to be confident while working with people with dementia.

Creativity at the heart of learning

Three PhD students from the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland (UWS) and Guildhall School collaborated with UWS staff, Stuart Wood (Research Associate) and Alzheimer Scotland to plan, organise and produce a series of online public seminars and complementary workshops.



The three seminars and workshops were delivered between November 2020 and January 2021 and focussed on creativity in dementia research. A PhD student presented at each seminar which was chaired by a member of UWS staff. The creative workshops that followed the seminars were facilitated by the non-presenting

PhD students. Content included the visual arts, music and song writing, and attendees included people living with dementia, their family carers and academics.

Feedback from the audience was positive, with sessions described as interesting and innovative with opportunities for self-expression. This experience inspired a presentation in the form of an interactive symposium at the British Society of Gerontology's 50th Conference 2021.

These opportunities helped students to express and discuss their research to diverse audiences, increasing confidence and self-belief.

2021 Gregory A, McLennan L, Beckwith C, Brown M, Wood S, Fulford H, Councill G, Ronan J, Sharp B. Creative Seminar Series. Presentations and workshops. University of the West of Scotland Online.

2021 Beckwith C, McLennan L, Gregory A, Brown M, Wood, S. PhD Dementia Research and the Creative Arts. Symposium. 50th Annual Conference British Society of Gerontology Online.

2021 Beckwith, C. 'Do You See What I See?': exploring collaborative songwriting to transform Young Onset Dementia carers' narratives (Saunders et al, 2015). Symposium. 50th Annual Conference British Society of Gerontology Online.

2021 McLennan, O. The Circle of Life: initial findings of research on intergenerational music-making in care homes through community music practice. Symposium. 50th Annual Conference British Society of Gerontology Online.

2021 Gregory, A. The Thing: understanding meaning in activities and interactions with people with advanced dementia through Stake's (2010) lens. Symposium. 50th Annual Conference British Society of Gerontology Online.

Trauma Informed Approach – Developments

Trauma occurs when an individual encounters a distressing experience or event that overwhelms the ability to cope with and make sense of a situation. An emotional and psychological threshold is crossed that has a profound impact on all aspects of an individual's life



The Scottish Government recognise the impact of trauma and are funding widespread awareness and training for the health and care workforce. For people with dementia and their families, past experiences, managing a progressive condition and everyday encounters, not to mention a pandemic, can increase the impact of trauma. With so many difficulties impacting upon people it is surprising that trauma-informed approaches to dementia care and support have received so little attention.

We feel it is important to address this gap and explore the benefits of trauma-informed perspectives applied to people affected by dementia. Before the pandemic, we had already been delivering trauma informed masterclasses with NHS Education for Scotland, now being delivered online. This year we have been working collaboratively with Alzheimer Scotland Helpline staff and volunteers to use trauma informed approaches (see more about this later in this Report). We have secured a UWS Vice Chancellor Innovation Award to establish online TIPA Resources (Trauma Informed Pedagogical Approach) in collaboration with students, staff and other stakeholders. We recognise the wide and long-term impact trauma and distress can have on individuals in all areas of their life. Therefore, being able to support staff and students in meaningful trauma-sensitive engagement within university learning and teaching underpins positive wellbeing creating a supportive and safe place for learning and growth.

Finally, the Scottish Neurological Research Fund has awarded us a research grant with fellow researchers and partners from the University of Dundee, University of Stirling, Edinburgh Napier University, NHS Education for Scotland (NES) and Alzheimer Scotland Helpline Team to develop our research programme entitled TrIAD: Trauma-Informed Approaches in Dementia. This research drives a synergy between policy, practice and applied research and will inform future strategies to mediate risk of re-traumatisation, minimise harm, engage in safe and meaningful collaboration and promote recovery for people with dementia, their families and those involved in their care.

Help in Covid Times: A Trauma Informed Approach to Helpline Practice

Partnership in action from the Centre and Alzheimer Scotland.

Throughout 2021, Margaret Brown and Jenn Hall have been providing co-created trauma informed learning sessions for Alzheimer Scotland helpline volunteers.

This really put into context what trauma is and what trauma informed practice is! ... I have made so many assumptions in the past where a trauma informed lens would have been so helpful. So definitely going to be keeping that at the forefront of my responses. So Volunteer

In March 2020 Scotland, like many other countries across the globe went into lockdown, a traumatic and uncertain time for 95,000 people living with dementia in Scotland and their carers. Support ground to a halt, therapeutic day care closed, Care Homes locked down.

Alzheimer Scotland's 24-hour Helpline was already there. For over 30 years, the Helpline and a dedicated team of highly skilled, homebased volunteers have been ready to listen. We had the infrastructure to be there for people who needed us as lockdown began.

As time went on and the situation worsened, calls became a narrative of "I can't cope anymore". We began to hear extreme distress from our callers due to bereavement, not being able to say goodbye. We spoke to carers and people with dementia who would regularly express thoughts of suicide and utter despair. The overwhelming sense of guilt that carers described was upsetting and difficult to deal with. Nothing could have prepared us for this. Since March 2020, calls to the Helpline have increased by 30%, with some call time increasing by 80%.

The increased intensity of the calls was taking its toll. Volunteers described feelings of helplessness due to the lack of resources. They expressed feelings of helplessness, guilt, and frustration at not having the answers or the ability to improve the situation for callers.

Jenn and Margaret met to reflect and this was a turning point. We considered the potential of a Trauma Informed Approach to Helpline practice. It seemed to fit well with experiences on the Helpline and an opportunity to build resilience and understanding of a trauma informed lens amongst the Helpline volunteer team.

This conversation led us to co-creating with our Volunteers, a meaningful learning opportunity that introduces Trauma Informed Approaches as a tool we can incorporate into our Helpline practice.

Yesterday I was able to speak to a caller whose husband is in a care home and has been very frustrated..., lashing out at the staff. We spoke about what might have happened when he wakes and sees a carer in his room. It was good to be able to do this, rather than make general suggestions like 'chat to the staff' or 'speak to the Dr.

Volunteer

The process of co-creation was incredibly valuable, the Team Leaders and volunteers had ideas to make this session as meaningful as possible.

The session *"Trauma Informed Responses to Helpline Practice"*, is an introduction, raising awareness of trauma in people affected by dementia. It provides a safe space for Helpline Volunteers to:

- connect and explore a trauma informed approach
- examine early trauma and current trauma for the person affected by dementia
- explore a personal and organisational trauma informed approach

There has been an instantaneous impact on Helpline practice. More than seventy percent of the Helpline Volunteers have completed the course and demand is high.

Thank you so much for enabling me to join the session — so worthwhile, even on a sunny Saturday morning! I thoroughly enjoyed it and found it so useful. Margaret explained it all so clearly, illustrating with examples from her years of experience. So Volunteer

Excited'. Maybe this doesn't sound like the most appropriate word but it's a new 'tool' in the helpline toolbox which I can use in responding to some of the very challenging calls. Solunteer

The early indicators of success have us striving to be a Trauma Informed Helpline. As usual our volunteers are driving us on too.

This is so valuable! AlzScot could include info in the carer packs and in other literature. Encourage all (are Home Providers to train all care home staff so they are sensitive to the possibility that there may have been a traumatic episode in the past causing frightening memories...Make this "best practice" in conjunction with (are Inspectorate – the training and life history.

Volunteer

With such great ideas, it is clear we can do so much more.

Carers' **Academy**

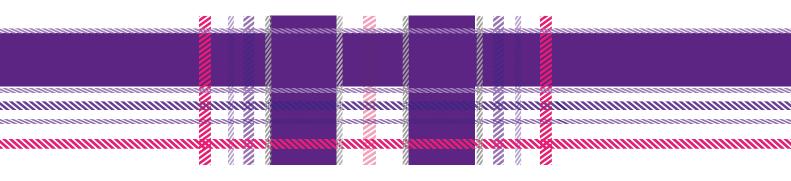
The COVID-19 pandemic has undoubtedly exacerbated the challenges of the family caring experience, whilst also further highlighting the fundamental importance of supporting both the person living with dementia and those who support them.

We are therefore delighted that partnership working with family carers to support the future development and expansion of the Alzheimer Scotland Centre for Policy and Practice (ASCPP) Carers' Academy, via our Carers' Academy Development board has been able to continue throughout the pandemic. This work, alongside funding received from Alzheimer Scotland has enabled us to once again re-open the doors of our Ayr Campus hub of the Carers' Academy. We are also thrilled to announce the opening of a newly established Carers' Academy hub within our UWS Lanarkshire Campus site.

Thanks to the support of the family carers who remain critical members of the Carers' Academy Development Board, a new carer-led Carers' Academy evaluation tool, which will be used to inform future planned future research activity has also been developed. Work to support the creation of a digital Carers' Channel which will be housed within the new Alzheimer Scotland Virtual Resource Centre has also been commenced. A longer-term plan to support the development of a digital Carers' Academy programme also remains a key ambition of the ASCPP.

SPICe spotlight has highlighted the potential of the ASCPP Carers' Academy to support the Scottish Government Dementia COVID Transition and Recovery Plan if rolled out across Scotland. This would certainly be the longer-term goal of the ASCPP and funding opportunities to support the spread and sustainability of this work in the longer-term continue to be pursued.

Find out more at https://spice-spotlight.scot/2021/01/21/protecting-those-at-risk-what-some-covid-19-experts-think



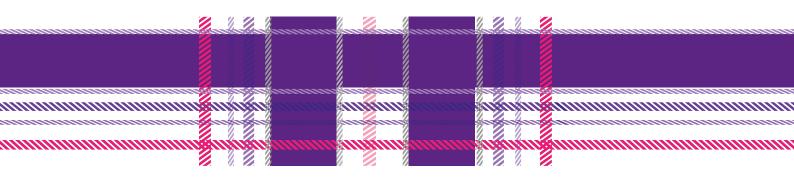
New ASCPP Research Grants

CO-PRODUCING A CAREERS GUIDANCE INTERVENTION FOR PEOPLE LIVING WITH DEMENTIA.

Dr Louise Ritchie, Professor Debbie Tolson, Dr Emma Bolger, Dr Laura Lebec (UWS), Dr Valerie Egdell, (Northumbria University), Professor Jill Stavert (Edinburgh Napier University), Professor Katie Brittain (University of Newcastle)

We were delighted this year to be awarded a 3-year research grant to develop our dementia and employment research programme. This research, funded by the Alzheimer's Society, aims to develop, and test an intervention to support people who are diagnosed with dementia to get support with continuing employment and with making decisions about their employment. We aim to do this by combining expertise from career guidance professionals, healthcare professionals and people living with dementia to produce a career guidance intervention to provide person-centred support for work-related decisions. This project will use an Action Research approach to engage practitioners, researchers and people living with dementia in the project process. Our previous research has demonstrated that people living with dementia can, and do, continue to work. However, many do not have this opportunity and some even face disciplinary procedures because of challenges they have had in doing their job.

Although it has been a few years in development, the project officially started in October 2021 when our new Research Fellow, Dr Laura Lebec joined the team. We are so excited that this project will begin to address a gap in support for people with dementia and we look forward to providing updates on the progress in years to come.



IMPROVING THE HEALTH AND WELL-BEING OF OLDER PEOPLE WITH DEMENTIA IN PRISONS

Dr Rhoda MacRae, Professor Debbie Tolson, Dr James Taylor, Dr Kirstin Anderson and Dr Natalie Chalmers (UWS), Dr Tom Russ and Professor Lindsay Thompson (University of Edinburgh)

Funded by the Dunhill Medical Trust, the aim of this 18-month study is to identify and develop new effective ways to improve the health and well-being of the increasing numbers of older people living with dementia in prison. Between now and Christmas we will undertake interviews with staff across the four prisons with the largest numbers of older prisoners so we can describe the current referral, diagnostic and post-diagnostic healthcare pathways and understand how later life well-being is promoted and health risks reduced. In the New Year we will interview prisoners living with dementia and their significant others to construct case studies to exemplify the dementia lived and care experience. The final phase, next summer will be to co-design an evidence informed referral, diagnostic and post-diagnostic healthcare and co-produce an evidence informed model for promoting later life well-being and reducing health related risk with stakeholders.

Although funding for the project was secured in 2020, the start date was delayed until Covid restrictions eased and our new research fellow Natalie Chalmers joined the team in June this year. We are really looking forward to working collaboratively with a wide range of stakeholders to produce tangible outputs that have the potential to improve the health and well-being of those living with dementia in prison.

TRAUMA-INFORMED HELPLINE

Trauma Informed Approach in Dementia (TrIAD): Understanding trauma within family based dementia care: an analysis of Telephone Helpline Calls.

Dr Eileen Harkess-Murphy, Dr Margaret Brown, Dr Rhoda Macrae, Dr James Taylor (UWS), Jen Hall (Alzheimer's Scotland), Dr Grant Fraser King (University of Dundee), Professor Thanos Karatzias (Edinburgh Napier University & NHS Lothian), Dr Brodie Paterson (University of Stirling), Jennie Young (University of Stirling & NHS Education for Scotland), Dr Margaret Conlon (University of Stirling)

Funded by the Scottish Neurological Research Fund we are very excited to be awarded monies to explore trauma informed approaches within the field of dementia. This project marks the beginning of the TrIAD research series at the Alzheimer Scotland Centre for Policy and Practice at UWS and is an important and necessary step that brings together best-practice within the wider health and social care field recognising the trauma that carers and care recipients experience. This project will analyse the helpline staff responses from the UK's only 24-hour dementia helpline (Alzheimer Scotland) to explore the extent to which the six trauma informed principles are evident within their responses (to carers and people with dementia). It is a multi-centre project that brings together a network of new interdisciplinary researchers, broadening the expertise in dementia research in Scotland. We look forward to reporting on the updates of this study and exploring the potential for future collaborations in trauma-informed approaches in dementia.

New Research Reports

THE COST OF SEPARATION: THE IMPACT OF VISITING RESTRICTIONS ON FAMILIES OF CARE HOME RESIDENTS DURING COVID-19.

A Rapid COVID Study Funded by Chief Scientists Office.

Palattiyil, G, Jain S, Hockley J, Jamieson I, McKie L, Mason B from University of Edinburgh; Sidhva D, Tolson D, Swift S from University of the West of Scotland; Quinn, Hafford-Letchfield T, University of Strathclyde; and Iversholt R formerly with IRISS.

This six month project was completed between May and October 2020. At that time there were approximately 36,000 adult resident in care homes in Scotland. 91% living in care homes dedicated to the care of older people, 65% requiring nursing care and approximately 50% living with dementia.

444 family carers completed the online survey which included the General Health Questionnaire (GHQ) to measure mental health and well-being in relation to care home lockdown experiences.



76% scored 12 or more on the GHQ, the threshold for clinical mental illness.

36 family carers participated in in-depth individual interviews.

From Fear to Frustration

- · Shut out, shut in
- · Profound loneliness and family life denied
- · No self-determination, abandoned
- Being harmed, fear, distress, no advocacy
- Lost last goodbyes
- Shock, disbelief, grief stricken, powerless, angry

19 semi-structured interviews were undertaken with a range of stakeholders including sector leaders, Scottish Government policy actors, regional partnerships, regulators and advocacy organisations.

Not prepared, Not Knowing, Not Listening

5 Creative Café's captured the frontline stories from staff of how they adapted and improvised in an attempt to keep families connected.

Mutual Respect and Empathy

Creative practice, between the rules, Staff keeping families connected

For more information see www.creativecovidcare.com

Institutional Seedcorn Fund: Living the best life possible

Dr Rhoda MacRae and Professor Debbie Tolson have been awarded an Institutional Seedcorn Fund by The RS Macdonald Charitable Trust. The Trust has prioritised this as their preferred model of funding for universities within their Medical Research funding stream, in recognition of its ability to unlock potential and invest in excellence. We are really pleased they have placed their confidence in the Centre and UWS.

The goal of the Seedcorn is to grow Early Career Researchers (ECRs) and capacity for innovative interdisciplinary applied dementia research within and across UWS. The Seedcorn fund will create opportunities for UWS ECRs and those new to dementia research, from any discipline across the four academic schools to develop their careers through working on applied dementia and dementia care research.

During 2022 we will hold the first competitive funding round. Each successful project will test or explore interdisciplinary ideas and interventions to support dementia care and those living with dementia to live the best life possible. There are five areas that will be funded under our theme 'Living the best life possible', these are:

- Care and living assistive technologies
- · Fitness and well-being
- Psychosocial interventions
- Positive living and care environments
- · Dementia and family caring

The RS Macdonald (haritable Trust have a longstanding interest in medical research which looks into both the care and treatment of neurodegenerative conditions. We were therefore delighted to have VWS show interest in our seedcorn model. The funding has every potential to spark interest from a number of early career researchers from across the University, whose expertise can be applied to dementia care. We look forward to hearing about the proposals as they come forward in 2022 and beyond.

Rachel Campbell, Director, RS MacDonald Charitable Trust

Time to Talk **Dementia Research**

The new academic year and launch of Scotland's first Brain Health and Dementia Research Strategy has given impetus to strengthening dementia research at UWS. In October we were delighted to be invited to share our work and invite others to get involved in dementia research through a Seminar hosted by the School of Business and Creative Industries. Through seminars and other ASCPP Open Events we are starting new conversations about interdisciplinary dementia research.

You can watch a recording of the session at https://www.youtube.com/watch?v=91ZhzC_1yVQ

It was a privilege hosting the seminar on Dementia Research: Everyone's Business. It was a well-attended event internally and externally and the participants found it very informative and inspiring. Dementia is indeed everyone's business and people with dementia and family carers deserve the best possible care and support.

Well done to Professor Debbie Tolson, Dr Louise Ritchie, Dr Rhoda Macrae and



the entire team of the Alzheimer Scotland (entre for Policy and Practice (AS(PP) for their innovative research in shaping the lives and supporting people with dementia. The work that has been carried out by the centre on dementia has been extremely exemplary and valuable.

Research on dementia is apposite and I am personally looking forward to supporting the Centre in developing more interdisciplinary collaborations in this space.

Dr Christian Harrison, Reader in Leadership, School of Business and Creative Industries, University of the West of Scotland

Scottish Dementia Research Consortium What's Been Happening? Scottish Dementia Scottish Dementia Research Consortium

At ASCPP we are fully signed up members of the Scottish Dementia Research Consortium (SDRC), which now has a membership of over 700 researchers from across Scotland. Professor Debbie Tolson and Dr Louise Ritchie contribute to the success of this ever growing consortium through their elected positions on the SDRC Executive.

SDRC COVID Mitigation Awards have taken the stress out of disruptions for four doctoral students at UWS who have received monies to help them with the additional 'things' that they need to keep their research on track. The SDRC focus on supporting our future research leaders has been exceptional, including informative webinars, opportunities to share through research blogs and to network across Scotland and a thought provoking conference.

Through the auspices of the SDRC Living with Dementia Research Theme, we work with members of the Scottish Dementia Working Group and National Carers Action Network, to ensure they are research involved and telling us about their research priorities. Throughout 2021, SDRC has published a series of blogs on Research Involvement providing perspectives on research involvement, written by family carers, and our Depute Director, Dr Margaret Brown who explained why research involvement is so important for the work we do in the Centre. The blog series has shown what can go well and not so well with research involvement and has started a great dialogue across the research community – 350 views so far!

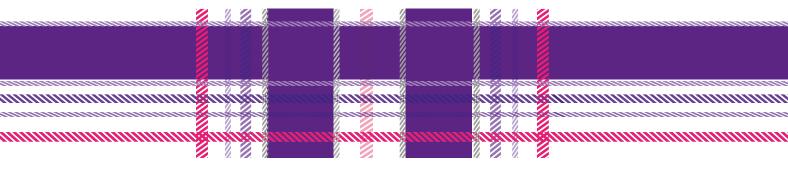
The message that we are 'all researchers' and have collective responsibility for getting dementia research into practice is the core message of Scotland's new Brain Health and Dementia Research Strategy. Professor Craig Ritchie, SDRC Chair who spearheaded the research strategy was a guest speaker at an ASCPP Open Centre Event, where he led a relaxed talk, followed by discussions with our students, staff and ASCPP associates and friends to help us understand how each of us can support strategy implementation and dementia research careers.



Professor Ritchie's take home messages for us were that firstly, the most important research is that which is most relevant to the needs and challenges faced on a day-to-day basis for people living with dementia and their loved ones and support network. Secondly, the NHS, social care and other large organisations need to be much more able to facilitate and support high quality research across all of Scotland and for all our communities, the establishment of local and a national research board will ensure this need is met. Finally, the scale of the highly trained and motivated workforce needed to design and deliver research cannot be a limitation on the needs of the communities we work with, so we need to look closely at how we develop and overcome blocks to having in Scotland the numbers needed of highly qualified researchers and academics to deliver on what is desperately needed.

The SDRC is a vibrant research community which is active in supporting and celebrating all types of dementia and brain health research across Scotland. It is free to join and open to everyone, whether you are a researcher in Scotland or not.

For more information go to https://www.sdrc.scot/join



New **Publications**

Bolger, E., Egdell, V. and Ritchie, L. (2021) 'Dementia in the workplace: the implications for career development practice'. *British Journal of Guidance & Counselling*, pp.1-10.

Brown, M. and Tolson, D. (2020) 'Introduction to living with advanced dementia series'. *Nursing Older People.* doi: 10-7748nop2020/e1169

Brown, M., Tolson, D. and Ritchie, L. (2020) Changing needs in advanced dementia. *Nursing Older People* doi: 10-7748-nop/2020/e1204

Diaz, A., Gove, D., Nelson, M., Smith, M., Tochel, C., Bintener, C., Ly, A., Bexelius, C., Gustavsson, A., Georges, J. and Gallacher, J. (2021) 'Conducting public involvement in dementia research: The contribution of the European Working Group of People with Dementia to the ROADMAP project'. *Health Expectations*. 24(3), pp.757–765. https://doi.org/10.1111/hex.13246

Egdell, V., Cook, M., Stavert, J., Ritchie, L., Tolson, D. and Danson, M. (2021) 'Dementia in the workplace: are employers supporting employees living with dementia?'. *Aging & mental health*, 25(1), pp.134-141.

Hockley, J., Hafford-Letchfield, T., Noone, S., Mason, B., Jamieson, L., Iversholt, R., Musselbrook, K., Palattiyil, G., Sidhva, D., Quinn, N., Jain, S., McKie, L. and Tolson, D. (2021) 'COVID, Communication and Care Homes: A Staffs' Perspective of Supporting the Emotional Needs of Families'. *Journal of Long-Term Care*, pp.167–176. DOI: http://doi.org/10.31389/jltc.74

Jack-Waugh, A., Henderson, J., Sharp, B., Holland, S. and Brown, M. (2020) 'Delivering personal care for people with advanced dementia'. *Nursing Older People*, 32(5), pp.1-15

Jenkins, N., Gorman, R., Douglas, C., Ashall, V., Ritchie, L., and Jack-Waugh, A. (2021) 'Multi-species dementia studies: Contours, contributions and controversies'. Journal of Aging Studies, 59, https://doi.org/10.1016/j.jaging.2021.100975

Jenkins, N., Monaghan, K. and Smith, M. (2021) 'Did they really say that? An agential realist approach to using computer assisted transcription software in qualitative data analysis'. *International Journal of Social Research Methodology.* https://doi.org/10.1080/13645579.2021.1965037

MacRae, R., Duffy, F.J.R., Lawson, B. and Brown, M. (2020) 'Learning and Leading in Advanced Dementia Care'. *Nursing Older People*. doi: 10.7748/nop.2020.e1189

MacRae, R., Macrae, E. and Carlin, L. (2020) 'Modifying walking football for people living with dementia: lessons for best practice'. *Sport in Society.* Accepted 15/09/20 DOI: 10.1080/17430437.2020.1825383

MacRae, R. and Papadopoulou, C. (2021) 'Managing a dual diagnosis of cancer and dementia in an acute setting: considerations, implications and future recommendations'. *Seminars in Oncology Nursing*. Accepted 19/10/21

McGarry, W., Wright, W., MacCallum, C., Brown, M., Ross, K., Ritchie, L., Mitchell, B., Coyle, L-A. and Tolson, D. (2021) 'Class in a Bag: A collaborative innovation in dementia'. Chapter 7. *CATE Collection: Together in Collaborative Educational Leadership.* An Advance HE UK Publication. Available at: https://bit.ly/3cABZv5

Mitchell, B., Jackson, A., G., Sharp, B. and Tolson, D. (2020), 'Complementary therapy for advanced dementia palliation in nursing homes'. *Journal of Integrated Care*. https://doi.org/10.1108/JICA-02-2020-0009 Mollah, M. and Alam, A. (2020) 'Situation of Social Compliance in the Readymade Garment (RMG) Sectors of Bangladesh: An Overview'. *The Journal of Social Development*, 30(01), pp.137-150.

Quinn, S., MacRae, R., Gifford, E., Rainey, H., Andrews, M. and Rooney, K. (2021) 'Quality Improvement in the Voluntary Sector: Knowledge, Capacity and Education'. *Voluntary Sector Review* (online 5 October 2021)

https://doi.org/10.1332/204080521X16311325629388

Ritchie, L., Egdell, V., Danson, M., Cook, M., Stavert, J. and Tolson, D. (2020). Dementia, work and employability: using the capability approach to understand the employability potential for people living with dementia. *Work, Employment and Society,* 0950017020961929.

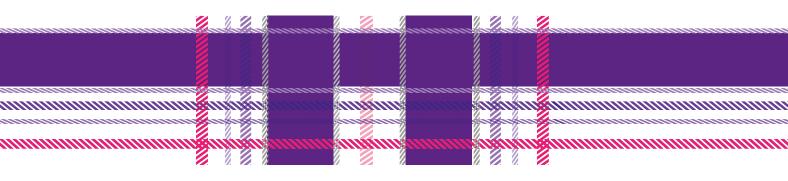
Ritchie, L., Jack-Waugh, A., Sanatombi Devi, E., V, B., George, A., Henry, J., Martis, C.S., Gangopadhyay, D. and Tolson, D. (2020), 'Understanding family carer experiences of advanced dementia caregiving in India: towards a vision for integrated practice', Journal of Integrated Care, Vol. ahead-of-print No. ahead-of-print. https://doi.org/10.1108/JICA-02-2020-0006

Ritchie, L., Quinn, S., Tolson, D., Jenkins, N. and Sharp, B. (2021) 'A realistic evaluation of the Dementia Dog Project: Exposing the mechanisms underlying successful animal-assisted interventions for people with dementia'. *International Journal of Social Research and Practice* 20(1) pp.66-83. doi: 10.1177/1471301219864505. Epub 23/7/19

Roddy, E., MacBride, T., Coburn, A., Jack-Waugh, A. and Dewar, B. (2021) 'Moving stories: exploring the L.I.F.E. session storytelling method as a way of enhancing innovative, generative outcomes in practice'. *The International Practice Development Journal* 11(1), pp.1-15.

Sharp, B., Henderson, J., Brown, M., Jack-Waugh, A. and MacRae, R. (2020) 'Palliative and end of life care in advanced dementia'. *Nursing Older People*. DOI: 10.7748/nop.2020.e1191

Smith, M., Brown, M., Ritchie, L., Papadopoulou, C. and Tolson, D. (2021). Living with Dementia in Supported Housing: A Systematic Review and Thematic Synthesis of Qualitative Research. *Health and Social Care in the Community*, Forthcoming.



Conference Presentations

2020 Gamble, C., MacRae, R., Jack-Waugh, A., Ritchie, L., Croudace, T. *A comparison of two dementia knowledge instruments.* SDRC virtual conference 7/9/20

2020 Jack-Waugh, A., MacRae, R., Ritchie, L., Brown, M., Sharp, B. *Scotland's Dementia Champions programme: education with the experience of people with dementia at its heart.* Alzheimer Europe-virtual conference. 20-22/10/

2020 Jack-Waugh, A, Ritchie, L., Tolson, D. *Inclusive and accessible advanced dementia education and development; from Scotland to India and back again.* 3rd National NMAHP Education Conference – a skilled and sustainable workforce for a healthier Scotland.

2020 MacRae, R., Macrae, E and Carlin, L *Evaluating the Social Impact of Dementia Friendly Walking Football*. Alzheimer Europe virtual conference.

2020 MacRae, R., Macrae, E and Carlin, L *Evaluating the Social Impact of Dementia Friendly Walking Football*. Rural Dementia Action Research Summit 2020, Canada.

2020 Roddy, E., Dewar, B. McLaughlin, A. and Jack-Waugh, A. *Knowing Me and Knowing You: There ARE Some Things We Can Do. Using creative resources to help us to get to know people living with dementia in care homes.* International Dementia Conference, Hammond Care, 2020.

2020 Tolson D. *Impact of COVID-19 on Older People*. Interactive Virtual Symposium. Manipal Academy of Higher Education, India.

2021 Brown, M., Woods, S., Gregory, A., Beckwith, C and McLennan, L. *Seminar: Creative Approaches in Dementia.* Research 50th Annual Conference British Society of Gerontology Online.

2021 Brown, M., Hall, J., Help in Covid Times. Alzheimer Scotland Annual Conference.

2021 Brown, M. McGarry, W. *The future of dementia care and housing.* Caledonia Housing Conference.

2021 Brown, M., Apurva, P. Ageing and Dementia. Seminar: Forensic Network Scotland.

2021 Jack-Waugh, A, Ritchie, L., Tolson, D. Sustainable Interprofessional working towards Advanced Dementia, research, workforce development and practice' (Inclusive and accessible advanced dementia education and development; from Scotland to India and back again). Global Symposium Series on "Collaborative Healthcare Practices & Challenges in Current Times" Manipal College of Nursing Manipal, MAHE, Manipal.

2021 Macrae R, & Jack-Waugh, A. Involving people affected by dementia in dementia education. Alzheimer Scotland Annual Conference

2021 Mohammad M, & Rabbani G. *The experiences of dementia and the future of education, research, policy and practice for people with dementia in Bangladesh.* Global Symposium Series on "Collaborative Healthcare Practices & Challenges in Current Times" Manipal College of Nursing Manipal, MAHE, Manipal.

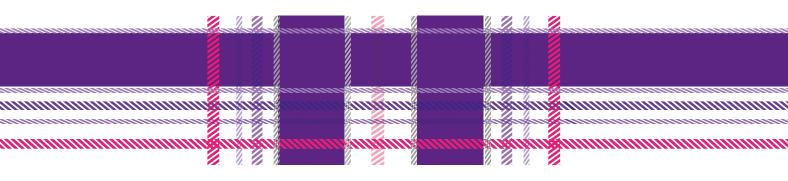
2021 Ritchie L, Tolson D. *Understanding Dementia Class in a Bag: a Resource to Educate on Brain Health and Dementia.* Workshop Presentation. Scottish Dementia Research Consortium Annual Conference.

2021 Ritchie, L., Brown M, Beckwith C and Wood, S. Singing in the moment: Exploring the experience of dementia inclusive singing activities for people living with dementia and family carers. Presentation. 50th Annual Conference British Society of Gerontology Online.

2021 Smith, M., Ritchie, L., Brown, M., Papadopoulou, C. and Tolson, D. *Living with dementia in supported housing: Findings from a systematic review and thematic synthesis of qualitative research.* Alzheimer Europe Virtual Conference.

2021 Tolson D, Holland S. *Dementia Care Research-Opportunities, Challenges and Current Realities.* Scottish Parliament Cross Party Group-Life Sciences. 15/6/21.

2021 Tolson D. *Advanced Dementia: the evidence-policy-practice cycle.* Global Symposium Series on "Collaborative Healthcare Practices & Challenges in Current Times" Manipal College of Nursing Manipal, MAHE, Manipal.



New **Grants**

2021-2022 Macrae R, Tolson. Living the Best Life Possible with Dementia. Institutional Seedcorn Fund. RS MacDonald Charitable Trust. £60,000 plus £10,000 UWS top up.

2021-2024 Ritchie L, Tolson D, Brittain K (Newcastle), Egdell V (Northumbria), Bolger E, Stavert J (Napier) Co-produced careers guidance intervention for people with dementia. Alzheimer Society £256,000.

2021-2023 Macrae R, Tolson D, Taylor J, Anderson K, Russ T (UoE), Thompson L (UoE). Improving the health and well-being of older people with cognitive frailty and dementia in prison. Dunhill Medical Trust £114, 785.

2020-2020 Palattiyil G (UoE) Jain S (UoE), Hockley J (UoE), Jamieson L (UoE), McKie (UoE), Sidhva D (UWS) Tolson D (UWS), Quinn N (UoS), Hafford-Letchfield T (UoS), Iversholt R (IRISS). Care homes, social distancing and behavioural changes – an assessment of the psychosocial impact of Coronavirus on families with relatives in care homes in Scotland Chief Scientist Office Rapid Covid Study £150,000.

2021-2022 Brown, M Narrative evaluation of the Occupational Therapy Home Based Memory Rehabilitation programme (OTHBMR) £4,700

2021-2022 Brown. M., Harkess-Murphy, E. Tolson, D., Taylor, J., Ion, R., Young, J., Ndzi, D. Trauma Informed Pedagogical Approach TIPA: developing a co-created resource £10,000

2021-2022 Harkess-Murphy, E., Brown, M., Macrae, R., Taylor, J., Hall, J., King, G.F., Karatzias, T., Paterson, B., Young, J., Conlon, M. Trauma Informed Approach in Dementia (TrIAD): Understanding trauma within family-based dementia care: an analysis of Telephone Helpline Calls £14,983

CPD & Consultancy

2020-2021 Brown, M. Consultancy NHS Education Scotland Palliative Care programmes £8,000

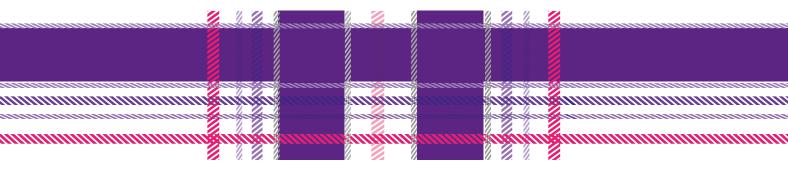
20-21 Jack-Waugh, A., Henderson J, Brown M, MacRae, R, Ritchie L. Funded by NHS Dumfries & Galloway Dementia Champions education. £15,000

20-22 Brown, M. Palliative care for people living with dementia. Funded by NES Education for Scotland. £6,300

2021 Dementia Training for the State Hospital. Funded by State Hospital. Brown, M. & Jack-Waugh, A. £4,700

2021-2022. Jack-Waugh, A., Tolson, D., MacRae, R., Duffy, R., Ritchie, L. & Brown, M., Henderson J. Dementia Champions online programme. Funded by NHS Education for Scotland. £75,000

2021-2022 Brown, M Jack-Waugh, A., Duffy, R., Mallay, S., McCallum, C. Henderson, J. Funded by NHS Education for Scotland: Complex care needs in dementia (DSIL programme). £15,000



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 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

For further information, please contact: Professor Debbie Tolson Director, Alzheimer Scotland Centre for Policy and Practice Email: debbie.tolson@uws.ac.uk

Contact us on social media

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We hope you've enjoyed reading about the (entre's work in 2021 and are excited to see what we can achieve together in 2022.





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