



University
of Worcester

Association for
Dementia Studies

CELEBRATING TEN YEARS OF THE
ASSOCIATION FOR DEMENTIA STUDIES.

"The Association for Dementia Studies has made an enormous contribution to improving our understanding of the experience of people living with dementia, and through their work they are increasing knowledge and changing lives."

Professor Martin Green OBE, Chief Executive,
Care England

Dementia has been labelled as the biggest health challenge of the 21st century. In 2009, the University of Worcester established the Association for Dementia Studies to help meet this challenge, and to enable people living with dementia, and their carers, to live better lives. The Association began with a single staff appointment, Professor Dawn Brooker. In the past 10 years, under Professor Brooker's leadership, the Association for Dementia Studies has flourished. Today, it is home to 20 multi-professional staff, a growing cohort of doctoral students, six honorary posts, and a steady stream of international visiting scholars. All of them are engaged in undertaking cutting edge research on how to deliver better care. The Association now has an established global reputation for its excellent research into person-centred dementia care. Its achievements locally, nationally and internationally have been remarkable and have been central to the transformation of care for people affected by dementia. A decade on, here are ten of the Association's most significant achievements.

Photo: Ruby Swift (TAnDem PhD student) undertaking a community singing group in 2017
(photograph by Cathy Greenblat)





"The Association for Dementia Studies at the University of Worcester has made a real difference to the lives of tens of thousands of people over these last 10 years. The Association has contributed so much to understanding what works in living well and caring better. I am very proud of all those members of the University who have contributed so much to this vital work."

Professor David Green CBE, Vice Chancellor and Chief Executive, University of Worcester

1

BRINGING PEOPLE TOGETHER – THERE IS NO US AND THEM

The Association for Dementia Studies is a multi-professional group, bringing together expertise from the fields of psychology, nursing, social work, gerontology, occupational therapy, policy analysis, medicine, primary care and psychiatry, with the experience of those living with dementia, their families and their carers, into one finely woven and richly textured conversation. Many organisations focus on research, policy, or education, but the Association is unique in integrating all of these diverse perspectives. The distinctiveness of the Association is due to a continued focus on working proactively at the interface between the experience of those directly affected by dementia (both the person and their carers), those developing care practice and those undertaking research to ensure real knowledge transfer and translation between these different world-views.

In 2018, the University made a joint appointment with the charity Dementia Carers Count, to employ Tracey Williamson as the first Professor of Family Care in Dementia at the Association for Dementia Studies, with a unique focus on the experiences, needs, interventions and outcomes for family carers.

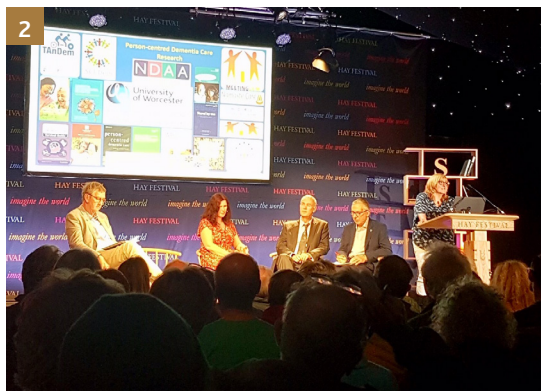
Staff from the Association provide education, coaching, training, and professional development to care home staff, domiciliary workers, GP's, primary care staff, hospital staff, community workers as well as many other health and social care professionals, whilst also feeding in to the learning of both undergraduate and postgraduate students at the University. The Association draws on its own research and the international evidence-base to deliver education programmes, resources and publications that empower people to provide skilled, competent and compassionate care.

"The best thing for me since being diagnosed with dementia has been meeting some inspirational people, and high on that list is Dawn Brooker. What Dawn passionately strives to do with her outstanding team is fundamental in seeking to achieve a care system which is truly person centred, and to do this based on good evidence derived from excellent studies and projects. I look forward to remaining well and to sharing future successes with the Worcester team under Dawn's leadership."

Keith Oliver, Alzheimer's Society Ambassador, KMPT (Kent & Medway) Dementia Envoy, 3 Nations Dementia Working Group, Young Onset Dementia National Network Steering Group, Author

"Ten years at Worcester is a wonderful achievement by Prof Dawn Brooker's whole team. Their pastoral role in supporting people in time of dementia, gathering those with dementia, their families, carers and friends into a community of hope is a fantastic aspect of their work."

Revd Jean Fletcher, Retired Mental Health Chaplain, Oxford



1: Presenting together at Hay Festival 2019: (L-R) Rik Cheston, Tracey Williamson, Dawn Brooker, Jeremy Hughes, Keith Oliver. Photo by Paul Musso.

2: Presenting at the Hay Festival 2019: *Dementia: The Biggest Health Challenge of the 21st Century*

3: Signing books together at Hay Festival 2019

2

NOTHING ABOUT US WITHOUT US

"It all started with a simple request for Ros and I to give a talk to nurses about six years ago. It continued like joining a happy family and the Association is still there acting as a life-raft for us both"

Roy Dibble, husband of Ros who lives with dementia: LINK group members



1: The late Peter Ashley (front right) in 2010 receiving an honorary degree from University of Worcester for services to Dementia Advocacy. Peter served on the Steering Group for the Association when it was first established.

People living with dementia and their families are often marginalised within society. The disability rights movement that advocates “nothing about us, without us” has been much slower to materialise in the dementia field compared to other disabilities. The Association has advocated for the rights of people living with dementia since its inception. The voices of those living with dementia, their families, and their care partners, are central to every element of the Association’s work, ensuring that their work remains firmly anchored in the experiences of the people it serves. In 2011 the Association established the LINK Group to provide the voice of experts by experience. Increasingly they now work in partnership with the organisations (Dementia Engagement & Empowerment Project [DEEP] and Together in Dementia Everyday [TIDE]) to support the participation of people and family carers in research and teaching. People with dementia and family carers are part of the selection panel for the Association’s academic staff, teach on many courses, and are part of every research programme, both on reference groups and as part of the research itself. This person-centred approach permeates all of the activities of the Association for Dementia Studies.



2: June and Brian Hennell, LINK Group members at the *Stand by Me* premier in 2011. Following Brian’s death in 2013, June established the Hennell Award in his memory which has been awarded each year to students of the university who have made a significant contribution to the lives of people living with dementia. June received an MBE in 2016 for services to dementia care.



3: The Association staff and Link Group in 2016

3 SPREADING THE WORD

Knowledge exchange is a technical term that can be loosely translated as ‘sharing what you know’. The Association for Dementia Studies is well aware that sharing knowledge and expertise is essential in order to turn good research in to excellent practice that genuinely improves the lives of people on the ground, but also appreciates that this is a two-way street, a conversation, not a monologue. The Association was a founder member of the National Dementia Action Alliance in 2010 which is now the leading independent network for health and care organisations to connect, share best practice and take action on dementia.



1: The team presenting at Alzheimer Europe conference 2016

Since 2009 the Association has published well over 100 pieces of original research in to dementia care, written and contributed to more than 40 books on the subject, and presented work at over 450 conferences worldwide.

"You welcomed me as a PhD exchange student. The placement proved vital for my professional development and international perspective"

Anders Møller Jensen, Klinisk Institut, Syddansk Universitet

"My time working for the Association for Dementia Studies at the University of Worcester has been one of the highlights of my career. I learnt so much while I was there, including the importance of a strong evidence base in practice. Dawn and the rest of her team also showed me that person centred care is achievable when we all work together."

David Moore, Operations Manager for Dementia, Methodist Homes Association

"It has been wonderful working with you, as partners for excellent conferences in Birmingham and Worcester in the early years, and now as greatly valued Academic Partners of the UK Dementia Congress."

Sue Benson, Managing Editor, Journal of Dementia Care

"What an impact you have made - Absolutely Fabulous. My appreciation includes the series of occasional lectures in my name. Giving people the chance to hear and meet key figures who have shaped the development of services and attitudes to people with dementia. Not run of the mill - but a lasting lesson of effective devotion and humility."

Professor David Jolley, University of Manchester



4

PROVIDING SKILLED CARE

Many professionals and care practitioners receive very little education and training in how to implement best practice. The Association has worked alongside national training and education bodies at a strategic level to improve this situation and contributed many accessible resources for staff working in the field. The Association has developed an excellent reputation for training and education programmes that make a real difference. Over the years, they have hosted 30 free events on dementia at the University of Worcester that have been open to the public and to professionals alike. Later this year, the Association will launch a brand new fully distance learning postgraduate programme in *Person-Centred Dementia Care*, opening up the opportunity for an international new generation of professionals to develop the leadership skills to play their part in shaping the future of person-centred care.



1: Illustration of Keynote presentation at British Gerontology Conference 2017 in Swansea

The Association has worked directly with 55 care providers to improve their dementia care, providing dementia care education programmes to more than 5,600 health, care and housing professionals from across the UK.

"You put together a bespoke, sector leading series of master-classes to give senior staff in our domiciliary care businesses leadership in dementia care that really delivered for our clients – and you nailed it!"

Mark Hamer, Managing Director Home Instead Senior Care Worcester

"The benefit to our service users and staff has been truly amazing."

Mark Wilson, Director of Engagement, Friends of the Elderly

"Working with Dawn and her wonderful team, who have a wealth of research-based knowledge, we gained clarity on where to focus our efforts in order to have the biggest, sustained impact."

Stephen Rees, Chief Operating Officer, RCH Care Homes

"We value our relationship with the Association confident that we are delivering the results of extensive and respected research into daily practice thereby creating communities where care is truly person centred."

Suzanne Mumford, Lead Quality Development Manager, Care UK

"We couldn't believe our luck when the Association opened in Worcestershire! We have seen an increase in the confidence of dementia care from the Care Homes who received training in 2010 and continue to see the benefit today as the staff have gone on to take up more senior roles."

Debbie Le Quesne, West Midlands Care Association

5 THE RIGHT TO A TIMELY DIAGNOSIS

With the numbers of those living with dementia world-wide increasing, the issue of when to diagnose and how this should be disclosed has become of great public concern. Ten years ago the national diagnosis rate for dementia was around 40% and people were being diagnosed late on in the disease process. The Association for Dementia Studies led the programme of work on developing public health advice on Early Diagnosis as part of the *EU Joint Action on Alzheimer's initiative (ALCOVE) programme* (2011-13). This research underpinned guidance for policy makers across the EU with the strong message that people had the right to an accurate diagnosis communicated sensitively and at a time when people and families could understand the implications of the diagnosis and make lifestyle changes to accommodate it. This project made evidence based recommendations for policy makers across the EU at a ministerial level. If people make good emotional, social and practical adjustments to dementia early, then it is likely that they will experience fewer distressing symptoms later, and will be able to live at home for longer with a better quality of life for them and their families. In 2019 the national average diagnosis rate is 70% with a national network of easy to access memory assessment services. The right to a timely diagnosis is now enshrined in national dementia strategies world-wide.

However, people often still feel overwhelmed and confused about where to get help. Support for families and for people affected by dementia is often fragmented and varies tremendously across the country. The Association's current research focusses on providing a better evidence base for post-diagnostic support. They were instrumental in securing funding for Worcestershire to host one of the first *National Demonstrator sites for Dementia Advisers* in the country in 2009, which now form the backbone of post diagnostic support across the UK. The Association led the NIHR funded *ASSET* project and were collaborators in the follow-on *ECHO* project, which delivered original research exploring how best to provide adult social care in housing with care settings across England with a focus on sustainability and efficient use of resources.



"The Association enabled us to shape innovative and ground breaking services delivered to families of people living with dementia"

Claire Goodchild, Chief Executive, Dementia Carers Count

1

"The Association for Dementia Studies has played an invaluable role in raising awareness of dementia over the last decade. Everyone whose life is touched by dementia has reason to thank the University of Worcester for its essential contribution to the dementia debate."

Duncan Jones, Trustee Alzheimer's Society



1: Dawn Brooker and Jeremy Hughes (CEO Alzheimer's Society) at 10 Downing Street at the launch of the Dementia Friends initiative in 2013

6 HOW TO MAKE FRIENDS AND...

At the heart of every Meeting Centre is a social club where people can meet to have fun, talk to others, and get the help and support they need.

1



"One of the most used phrases when I talk with people attending Meeting Centres is 'I enjoy coming here'. Giving someone back their self-esteem and a level of independence when they live with dementia is quite a challenge but the Meeting Centres ethos helps achieve that. We are delighted to be working in partnership with the Association of Dementia Studies at the University of Worcester, to practically help people directly affected by dementia."

Philip Talbot, Chief Executive, Age UK Herefordshire and Worcestershire

1: Members at Leominster Meeting Centre enjoying their time together

MEETING CENTRES

Diagnosis at an earlier stage means that there is an opportunity to ensure people and families make the best adjustments to living with dementia in the longer term. Meeting Centres offer expert advice, social engagement and a vital point of contact for people and families affected. Meeting Centres were originally developed in the Netherlands and Professor Brooker's team were part of a large European research programme to evaluate this innovation in the UK, Italy and Poland. The MeetingDem research showed that Meeting Centres significantly improve self-esteem, levels of happiness, and a sense of belonging, as well as reducing some of the most distressing symptoms of dementia and providing an invaluable source of support for family carers. In 2018 the Association secured funding from the National Community Fund to create a network of Meeting Centres across the UK. The team are now on their way to the target of 20 new Meeting Centres over the next 3 years.



2: Family members from Droitwich Spa Meeting Centre enjoying a canal trip

3: Some of the International MeetingDem Research team in Amsterdam June 2018:
L-R Katarzyna Lion, Franka Meiland, Dorota Szcześniak, Joanna Rymaszewska, Rose-Marie Dröes, Dawn Brooker, Elisabetta Farina and Shirley Evans

7

SUPPORTING PEOPLE AT LATER STAGES OF DEMENTIA

Research and development work at the Association in defining *Person-Centred Care (the VIPS Framework)* underpinned the NICE [National Institute of Clinical Excellence] *Guideline on Dementia* in 2007 and was retained in the most recent Guideline in 2018. The NICE Guideline offers best practice advice on care and support for people living with dementia and their families and carers. All too often people are prescribed sedating medication that have serious side effects and rob people of their quality of life. Research and education programmes pioneered by the Association and its partners have shown dramatic reductions in the prescriptions of sedatives by supporting staff to deliver person-centred care. Since 2016, practitioners have been able to study at the University of Worcester at Master's level to lead this approach within their own care organisations. Care providers that have participated in this programme have gone on to achieve national recognition for their work and some have been awarded Outstanding by the Care Quality Commission.

People living with the advanced stages of dementia are particularly vulnerable to poor quality care. The Association for Dementia Studies has just completed a 3-year implementation research project on Namaste Care. Namaste Care is a multi-component intervention developed in the USA shown to reduce distress behaviours, pain, use of antipsychotics and hypnotics, depressive symptoms and inappropriate hospitalisation in people living with advanced dementia. The results of this research will improve the care for those living with the most advanced stages of dementia.

"The team always offer a wealth of knowledge, encouragement and tenacity."

Caroline Baker, Director of Dementia Care, Barchester Healthcare

"The bespoke masterclasses from the Association on end of life and frailty have been well received and continue to enhance knowledge and skills for Admiral Nursing."

Dr Hilda Hayo, Chief Admiral Nurse and CEO, Dementia UK

"Recent research into the Namaste Care intervention shows some truly inspiring results of what can be done to support people living with very advanced dementia."

Isabelle Latham, Lead Researcher, Namaste Care UK Implementation Programme



1: Mary Tasker, manager of the Hawthorns Care Home in Evesham and Hennell Award winner 2019, celebrating an "Outstanding" rating from the Care Quality Commission. Pictured here (second right) with her team.



2: Scenes from the Association for Dementia Studies award winning film *Stand by Me* which now forms a free resource produced by Skills for Health.



The Association has long championed research into innovations that people and carers say are having a beneficial impact. The Association has launched a range of collaborative projects to explore the role that the creative arts, nature and sport can play in enriching the lives of those affected by dementia. Whilst many people use music, art, movement, sport, enjoying nature to enrich their lives, the Association for Dementia Studies has been building research in this area, testing each concept rigorously, and creating an invaluable evidence base that will help identify which approaches are most effective, and why. In 2015, the Association was funded by the Alzheimer's Society to have a Doctoral Training Centres with a focus on creativity and the arts to help increase research knowledge and capacity. TAnDem (The Arts and Dementia) has been a successful partnership between Worcester and Nottingham Universities and the next year will see the successful completion of all 8 studentships.

"The fantastic TAnDem (the Arts and Dementia) partnership between Worcester and Nottingham has been a great experience. We have really interesting findings and wonderful students. A real highlight for all involved."

Professor Tom Denning, University of Nottingham



1: Image taken from a graphic narrative constructed and illustrated by Emma Lazenby of ForMed Films CIC and based on interviews conducted as part of original PhD research by Karen Gray, TAnDem student.

2: Chris Russell, PhD student, meeting Sergei Aschwanden, Directeur, Centre des sports de Villars, Switzerland, May 2018. Finding out about how leisure is enacted in Switzerland.

9

MAKING PLACES AND SPACES DEMENTIA FRIENDLY

The places that people live are important to maintaining wellbeing. The Association hosts the Housing Dementia Research Consortium and holds an annual conference aimed at the housing sector. The research undertaken includes, for example, evaluation adaptations for people living in their own home. The use of technology and the physical environment are threaded throughout the team's research and education activities. The Kings Fund Enhancing the Healing Environments assessment tools moved to the Association for Dementia Studies in 2015 and the work continues by creating new assessment tools for a multitude of health, care and social spaces.

We have a long-standing interest in programmes that bring together children and people living with dementia. We evaluated the Intergenerational Schools project in 2012, set up to improve dementia awareness and reduce stigma by working with school age children and contributed to developing materials that could be used by teachers of different age-ranges. The award winning Dementia Dwelling Grants provided by Worcestershire City Council was evaluated by the Association of Dementia Studies and is now a well-established foundation for care within the County. We have also worked with Anchor to explore the value of touch-screen technology for people living with dementia in care homes, an area that offers great potential to enhance the quality of care provision.

The Association has also developed a programme of research exploring the impact of 'green dementia care', including an exploration of opportunities for people living in supported housing to engage with nature, and an evaluation of the social franchise model being piloted by Dementia Adventure, the leading UK provider of training and support for recreation and leisure sector providers of outdoor activities for people living with dementia.

H | D | R | C

**Housing and Dementia Research
Consortium**

The use of technology and the physical environment are threaded throughout the team's research and education activities.



1: In conjunction with the Alzheimer's Society, a booklet based on work by the Association was designed to help people with dementia living at home make changes to their accommodation

2: People enjoying a "green-care" experience in 2018; courtesy of Association collaborators
Dementia Adventure

"It's been a privilege to work with the Association for Dementia Studies, who have been so important in making sure people with dementia are not forgotten and teaching us that a society that is good for people with dementia is good for all of us."

Michiko Nakagawa from Japan

10 GOING GLOBAL

The Association for Dementia Studies is part of the global network of person centred dementia care. Dementia is a challenge for all post-industrial societies and by 2040 71% of people living with dementia will be from low and middle income countries. Partnership working extends across country boundaries and many staff work collaboratively with partners in other countries. Publications from staff are widely accessed in Australia and North America and key texts have been translated into Japanese, German, Spanish and Portuguese. The team have also been actively involved in the G7 Action of Dementia and with the Action Against Dementia under the auspices of the World Health Organisation, providing evidence on person-centred dementia care in 2015 and 2018. One of our successful PhD students, Michal Herz, who worked at the Association is now working for the *World Health Organisation on the Global Dementia Observatory*. Professor Brooker and her team have a longstanding relationship with dementia care practitioners and researchers in Japan where their work on person-centred care inspires many.



1: First WHO Ministerial Conference on Dementia 2015. Photograph for the #GlobalDementia campaign

2: Speaking at the British Embassy in Tokyo 2018

The team regularly works with colleagues from Japan, Australia, USA, Canada, South Africa, Singapore, Netherlands, Germany, Denmark, Norway, Spain, Portugal, Belgium and Italy.

"Prof Brooker's special lectures in 2012 and 2017 given in Tokyo at the Japanese Society for Person-Centred Dementia Care are the most memorable projects carried out by our NPO. Do you remember Dr Hasegawa? He was diagnosed with dementia and made it public by himself two years ago. He sent me a postcard after the 2012 lectures and told me that he enjoyed that day very much, especially having a talk with Dr Brooker at lunch. Lots of people love him dearly and respect him even now."

Yasuko Murata, Japanese Society for Person-Centred Dementia Care

"We are extremely fortunate to have the world class Association for Dementia Studies at the University. This Association has already made a huge difference. I am delighted to join in with and support the 10-year anniversary celebrations acknowledging the exceptional work of this local centre. Congratulations on your first decade."

Robin Walker, Member of Parliament for Worcester

"Professor Dawn Brooker is a rare individual who easily and seamlessly combines academia with love. The results are inspiring leadership in the field of dementia, imbued with love and care."

Chris Harding, Daily Sparkle

ACKNOWLEDGEMENTS & THANKS

Putting this booklet together has been a labour of love. Ten years at the Association for Dementia Studies has taught me many lessons about the importance of team work. Although it is often me and the other senior academics at the Association who get our photographs taken, or our names associated with publications, we have a fantastic team both within the Association, the School of Allied Health and Community and the wider university that make our work world-class. All our achievements are the result of this team pulling together. All of us actively engage with others who are striving to make the world a better place for all those affected by dementia. I'd like to thank everyone who has contributed to our achievements over the years. I'd particularly like to thank our University Comms team and all those who provided such lovely quotes and photographs for this publication.

Professor Dawn Brooker PhD CPsychol (clin) AFBPsS
Director of the Association for Dementia Studies



Second edition: September 2019