

Impact case study (REF3)

Institution: University of Northampton		
Unit of Assessment: 2 - Public Health, Health Services and Primary Care		
Title of case study: Improving Social Cohesion, Wellbeing and Quality of Life through Lifelong Learning Models for People with Dementia and their Carers		
Period when the underpinning research was undertaken: September 2013 - December 2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Jacqueline Parkes	Professor	2002 - present
Alison Ward	Senior Researcher	2010 - present
Michelle Pyer	Senior Researcher	2005 - present
Period when the claimed impact occurred: June 2016 – July 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact

Researchers at the University of Northampton's (UoN) Dementia Research and Innovation Centre (NDRIC) have researched, designed, and implemented unique national and international community-based post-diagnostic support groups for people with dementia and caregivers. Underpinning all of NDRIC's work is a commitment to ensuring that 'voices' of people with dementia and carers are central to the research, health/social care and service-delivery. Through innovations that actively promote social integration and normalisation, our researchers have co-developed a range of policy and practice impacts which have demonstrably improved community-based service provision for people with dementia and their caregivers. NDRIC research has also led the development of new models for Lifelong Learning in the United Kingdom (UK) and internationally.

2. Underpinning research

NDRIC, led by **Parkes**, has produced a research portfolio focused on the provision of community-based psychosocial support for people with early-stage dementia and their caregivers. In 2013, NDRIC established its first group, the Forget-me-nots. The group's purpose and format was based on a key message to emerge from the 'Your Voice Survey' conducted in 2012 [3.1] to understand the needs of people experiencing young onset dementia from their perspective. Survey participants said they wanted to be "*more actively supported in re-building normal social networks following initial diagnosis*" [3.1]. This became the first of two central aims underpinning the work of NDRIC. The second aim, taken from the central premise of Parkes' "Partners in Projects Model" [3.2], was for the NDRIC team to work in partnership with people with dementia and carers to design, develop, implement, and evaluate contemporary and innovative approaches to person centred community-based care and support.

Developing a Social Support Model for people living with early-stage dementia and carers

Established in January 2015, the development of the Lutterworth Share and Care Group (LSCG) was directly influenced by the Forget-me-nots Project. **Professor Parkes** completed a similar 'Your Voice' survey as part of a wider consultation process in South Leicestershire, where there was limited access for social support for people with early-stage dementia and their carers living in the community. The group rapidly expanded from hosting two coffee mornings per month in a local venue to delivering a programme of activities up to five days per week to over 50 people with dementia and carers. In 2017, an independent review of LSCG was commissioned [5.1]. The conclusions and recommendations contained within the LSCG research directly informed

the design, development and implementation of the Northampton UnityDEM (Centre for People Living with Dementia) Project (2018- 2020).

2.2 Designing and piloting a psychosocial support model for people with early-stage dementia and carers.

UnityDEM was a UoN Changemaker funded community-based project providing post-diagnostic support for people newly diagnosed with dementia. Thirty couples attended a programme of creative and physical activities in a non-medicalised community setting, three days per week. Evaluative data was collected using recognised measures i.e., Addenbrooke's Cognitive Examination (ACEIII), Model of Human Occupation Screening Tool (MOHOST), Obstructive Sleep Apnea (OSA), Dementia Quality of Life Measure (DEMQOL Version 4), and Bristol Activities of Daily Living Scale. Early findings clearly demonstrate that carers felt supported, and people with dementia showed improved confidence despite indications of ongoing cognitive decline [5.2, 5.7].

Introducing the Danish Life-long learning Model for people with early-stage dementia in the UK.

In addition to their work locally, researchers from NDRIC are working with colleagues at the University College of Northern Denmark to build an evidence base for a lifelong learning service for people with early-stage dementia [3.3]. **Dr Ward**, funded by the Winston Churchill Travelling Fellowship, worked with a Danish School's 'students' with dementia to help them tell their stories of participating in the service [3.4]. Building on the 'Partners in Projects' model, the researchers supported students to design and develop their own research projects, which resulted in a new participation model - 'Balanced Participation' [3.5]. Both studies have led to a greater understanding of this new service and how to actively engage people with dementia in research. **Ward** and the Danish School also completed a mixed methods pilot study using validated measures to identify the impact of lifelong learning on cognition, quality of life and socialisation for people with dementia. This was compared to a control group of people with dementia who attended treatment as usual. The pilot identified the effect size and most appropriate measures to use for a future larger study and informs the way people with dementia can be supported when using validated measures.

In establishing our social support and life-long learning models, our research demonstrates that people in early-stage dementia can gain in confidence and in some cases acquire new skills via active engagement in cognitively stimulating activities, social support groups, and life-long learning opportunities, thereby enhancing quality of life and enabling them to continue to engage in their communities.

Designing a national 'Good Practice Guide' for diagnosing people with Young Onset Dementia (YOD)

Parkes co-led The Angela Project (2017-20) funded by the Alzheimer's Society, and in partnership with Dementia UK and Young Dementia UK. This was the largest UK study of YOD and investigated how the accuracy of diagnosis and post-diagnostic support can be improved. The views of professionals, people with dementia and carers, and service providers were captured to understand the post-diagnostic support needs. The initial output was the production of the 'Good Practice Guide'. **Parkes'** role in this study was to set up the Project's Public and Patient Involvement (PPI) Forum. Its formation was informed by the Partners in Projects PPI Model of Training [3.2] and the Balanced Participation Model [3.5] and input from its members has made the resulting 'Good Practice Guide' [3.6, 5.4, 5.5] informative and accessible.

3. References to the research

[3.1] **Parkes, J., & Ward, A.** (2015). The Forget-me-nots Social Group for People with Young Onset Dementia and their carers: Celebrating the group's success one year on. *Journal of Dementia Care*, 23(4), 20-21.

[3.2] **Parkes, J., Pyer, M., Wray, P., & Taylor, J.** (2014). Partners in projects: preparing for public involvement in health and social care research. *Health Policy*, 117(3), 399-408. <https://doi.org/10.1016/j.healthpol.2014.04.014>

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- [3.3] Ward, A., Sorensen, K. A., Kousgaard, H., Schack Thoft, D., & Parkes, J. (2020). Going back to school – an opportunity for lifelong learning for people with dementia in Denmark (Innovative practice). *Dementia*, 19(7), 2461-2468. <https://doi.org/10.1177/1471301218763190>
- [3.4] Ward, A., Schack Thoft, D., Lomax, H., & Parkes, J. (2020). A visual and creative approach to exploring people with dementia's experiences of being students at a school in Denmark. *Dementia*, 19(3), 786-804. <https://doi.org/10.1177/1471301218786636>
- [3.5] Schack Thoft, D., Pyer, M., Horsbol, A., & Parkes, J. (2020). The Balanced Participation Model: Sharing opportunities for giving people with early-stage dementia a voice in research. *Dementia*, 19(7), 2294-2313. <https://doi.org/10.1177/1471301218820208>
- [3.6] Oliver, K., O'Malley, M., Stamou, V., La Fontaine, J., Oyeboode, J., Carter, J., & Parkes, J. (2019). Living with young onset dementia and actively shaping dementia research – The Angela Project. *Dementia*, 19(1), 41-48. <https://doi.org/10.1177/1471301219876414>

The “Partners in Projects Model” was developed from the findings from a series of externally funded studies; Trent Research and Development Support Unit funded a joint project between the local mental health trust and the University to develop research training for a group of people with a learning disability; St Andrews Healthcare, Northampton, funded a study in which women in a secure mental health hospital were trained to develop their own projects; and Nene Commissioning funded the ‘pilot’ Partners in Projects training programme [3.2]. The model also formed the basis for a unique joint PhD between the University of Northampton, Aalborg University DK, and the University College of Northern Denmark [3.5]. Based on the format of Parkes “Partners in Projects Model” [3.2], she developed and led the PPI workstream in the Alzheimer’s Society Funded “Angela Project” [3.6]; and [3.4] was the result of a project part funded by a Winston Churchill Travelling Fellowship (2015).

4. Details of the impact

The NDRIC team have built a strong portfolio of research focusing on early diagnosis and community-based post diagnostic interventions for people with dementia and carers. These interventions can enhance self-confidence and esteem, support existing cognitive abilities, promote social integration and the maintenance of social connections. This work has led to the evolution of new local and regional social support groups which continue to support over 100 people with dementia and carers to live well for longer at home. Such groups offer positive social support and a way to engage in meaningful and enjoyable activities according to the independent reviews of the Forget-me-nots [5.6] and LSCG [5.1] programmes. Gaps in current service provision were identified, which led to establishing two new social support groups in Northamptonshire and South Leicestershire.

Underpinning all the work of NDRIC has been a commitment to ensuring that the ‘voices’ of people with dementia and carers are central to the process as demonstrated by the creation of the Partners in Projects Approach, the Balanced Participation Model, and the Angela Project PPI Forum.

Supporting people with dementia and their caregivers by meeting a gap in existing social provision for this group.

a. The Forget Me Nots Social Group (2013-ongoing) was set up following a joint county wide consultation with people with young onset dementia who reported a gap in the provision of services for their needs, with a focus on being able to do social and normalised activities. It continues to meet the needs of people with dementia and their caregivers through monthly social meetings. In 2018, independent researchers carried out a mixed-methods evaluation of the group’s impact, with a focus on social connectedness [5.6]. The evaluation findings demonstrated that the development of a safe environment for both carers and people with dementia benefited the members through increased social bonds, autonomy and personal empowerment. Carers also experienced a sense of normality and enhanced social time:

"We have both enjoyed the group and it has provided a safe environment for [my wife] to socialise with people who fully understand her difficulties in communicating. It has also been extremely enjoyable when we have held events which have been attended by family members." (Carer 4)

"Both [wife] and myself have enjoyed our involvement with the Forget Me Nots and have become friends with people we would otherwise not have met. We have benefitted from sharing experiences with these people and it has helped us realise we are not alone" (Carer 4) [5.6]

b. The Lutterworth Share and Care Group (2015-ongoing) was established in Leicestershire in January 2015 following a local scoping review conducted by the General Practitioner Service. 160 diagnosed people with dementia were identified in the town. A community consultation led by **Parkes** indicated that over 40 people with dementia, carers and volunteers felt there was considerable unmet need for additional community-based social support. Chaired by **Parkes**, a steering group was established, local community funding secured, and LSCG was launched. Originally offering support over two mornings a month, the group has significantly expanded its activity programme in subsequent years. The group currently meets the needs of over 60 people with dementia and carers, former carers, and volunteers. An independent evaluation of the group, conducted by **Ward** in 2017, found it had a strong person-centred ethos, drawing on the strengths of the individuals. Essential to the group's success is being able to tailor the activities to suit the person with dementia, the carer, or both. These activities also provide opportunities for time away and respite for family carers:

"...it's a bit of respite for me to go in and talk to everybody, have a bit of a laugh and everybody's in a different state but all participate." (Carer 2)

"That there's somewhere safe for the carers to take their family members. That there's continuity in it that these people need something that's regular and on time and that we can supply..." (Volunteer)[5.1]

Additionally, the group provided participants with a way to find out about other services and support. Overall, it has increased member's social engagement, positively reinforced individuality, and provided access to meaningful and enjoyable activities to support cognition, activities of daily living and quality of life [5.1]. Recommendations from the independent review [5.1] have informed the future direction of LSCG. The Project Team have formed the not-for-profit Company, the Academy for Dementia Research and Education Ltd (ADRE) who continue to manage the LSCG project.

c. Northampton UnityDEM Project (2018-20). Findings from the Forget-me-nots and LSCG projects influenced the overall study design of the Northampton UnityDEM Project (2018-20). Early results and recommendations from this project [5.2] were incorporated into the revised Northamptonshire Dementia Strategy in 2019 [5.7] by the Clinical Commissioning Group Dementia Lead in conjunction with **Parkes**. The project officially finished in March 2020, early findings were collated into a Business Case Report [5.2] and presented to the local Clinical Commissioning Group Dementia Lead, Commissioning Manager, and local Mental Health Foundation Trust representative in September 2019 to support the case for further project funding. The outcome has been the development of Northamptonshire Dementia Hubs based on the UnityDEM Model following a County-wide Dementia Pathway Review during 2019/20. See Appendix 1 of the Revised Northamptonshire Dementia Strategy [5.7].

The UnityDEM Project has also influenced the evolution of UK-based Meeting Centre Support Programme (MCSP) via **Parkes'** membership of the UK Meeting Centre Reference Group [5.4, 5.8]. Hosted by the Association for Dementia Studies at the University of Worcester this project has established 13 new Meeting Centres across the UK, with 25 organisations working closely with the Association for Dementia Studies to develop further programmes. An early adopter of some elements of the MCSP approach, findings from the UnityDEM project have contributed to

the production of the “Essential features of a Meeting Centre: UK Meeting Centres Support Programme Booklet” (Nov 2019 edition) [5.8].

Inspiring new Models for Lifelong Learning in the UK and Internationally

Research conducted with the Danish lifelong learning service [3.3, 3.4, 3.5] provided teachers in Denmark with new approaches to working with people with dementia in a community-based setting. According to a special education teacher at the Aalborg Dementia School, the school:

“benefit[ed] from the collaboration with University of Northampton, and the teachers at Aalborg Dementia School have used the experiences from the projects to improve the education of people with dementia” [5.9].

As reported by the teachers, the success of the “collaboration has led to the opening of twelve similar dementia schools in Denmark, Norway and England” (ten in Denmark, and one each in Norway and England) [5.9]. The research increased the school’s media profile and the profile of the lifelong learning model. This has led to greater interest from policy makers and politicians in Denmark and Norway, which has helped the school to recruit more people with dementia and establish an international collaboration to develop the lifelong learning concept, agree standards of shared practice [5.3]. This has expanded the provision of services that support people with dementia in all three countries, by providing an innovative new approach through the lifelong learning model.

Working in collaboration with the Danish team, an NDRIC/ADRE Ltd partnership have been able to introduce the innovative and unique Lifelong Learning Model into the UK. Community-dwelling people with dementia started attending classes in Leicestershire in March 2019, providing the first UK lifelong learning school of its kind [5.9]. Testifying to the importance of research on the development of the UK Centre, the Lead describes how exchange visits and the subsequent publications have been “vital in developing the activities for the pilot group in the UK and the ethos of the staff involved in delivering the sessions” [5.10].

Developing a national resource for diagnosing young onset dementia

This primary output from the ‘Angela Project’, the ‘Good Practice Guide’, has been distributed via the Young Dementia Network (YDN) since March 2020. It has been downloaded a total of 561 times by 379 people. 63 paper copies have also been requested. In a YDN Survey conducted in October 2020, members reported that the resource was good. A separate survey has since been distributed to obtain more detailed feedback about all the YDN’s resources, including this ‘Guide’.

5. Sources to corroborate the impact

- [5.1] Ward A. & Hart, T. (2018) The Lutterworth Share and Care Group Evaluation Final Report.
- [5.2] Parkes J Project UnityDEM Centre-The Business Case Sept 2019
- [5.3] Minutes of October 2020 Dementia Working Group Meeting for Lifelong Learning
- [5.4] The UK Meeting Centre Presentation [29th May 2020]
- [5.5] Good Practice in Young Onset Dementia: Improving Diagnosis and Support for Younger People with dementia. <https://www.youngdementiauk.org/angela-project>: YDN Survey October 2020.
- [5.6] Sixsmith, J., & Kotterbova, E., (2017) The Forget-me-nots Evaluation Report.
- [5.7] Howsman, T. & Parkes, J. (2019) The Revised Northamptonshire Dementia Strategy
- [5.8] Northampton and Leicestershire Projects: influencing the UK MCSPs.
- [5.9] Letter of support from Danish Dementia School
- [5.10] Letter of support from UK Dementia School