

## INTERVIEW

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# Future of dementia care: an economic perspective



**Martin Knapp\***: Martin Knapp is Professor of Social Policy at the London School of Economics and Political Science, UK, where he directs the Personal Social Services Research Unit and co-directs the London School of Economics Health and Social Care, a center with more than 70 researchers. He is also Professor of Health Economics at King's College, London, UK. Since 2009, he has also been director of the National Institute for Health Research School for Social Care Research.

**Q** Coming from an economics background, how did you come to specialize in the fields of mental health, long-term care &, in particular, neurodegenerative diseases?

The short answer is almost by accident! When I finished my postgraduate education and was looking for a job, I was offered a position looking at the economics of social care and I have continued in the field ever since; I have now been working in the social care field for approximately 36 years. In the mid-1980s, I started working in the mental health field, which I had not done before then, initially with a couple of studies looking at the closure of long-stay psychiatric hospitals. Through this, I started to get increasingly interested in the mental health area and also the dementia field. In the last 20 years, there has been a rapidly growing need and demand for economic evidence and I have been in the field long enough to make a range of contributions.

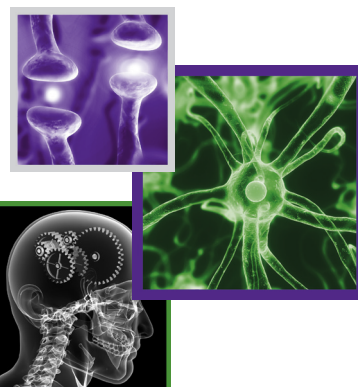
**Q** What are your current main areas of research?

I work in two main, very broad areas: social care (sometimes called long-term care) and mental health. At the moment, I have over 100 research projects, which

I am working on or responsible for, and approximately 15 of those are in the dementia area. My group works across the whole of the mental health spectrum, usually carrying out economic evaluations and policy analyses.

**Q** What is the greatest advance you have witnessed during your time in the field?

I am going to put two things together that apply to both the fields of mental health and social care. One is the recognition of those who use services as individuals. When I think back to the work we were doing on the closure of psychiatric hospitals (in the 1980s and 1990s), many of the inpatients were treated quite badly in hospital and the alternative arrangements for them in the community often left a lot to be desired. In particular, they were given few choices and had no control over their lives. Respect and dignity were often absent. There is still much to be done, but there have been substantial improvements. The second advance is linked: social and public attitudes have changed in relation to conditions such as schizophrenia, depression and dementia, with generally less stigmatizing attitudes now evident, although again, there is some distance to go.



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Journal Watch

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**Q In your opinion, what has been your most significant academic achievement to date?**

In one word, survival! I am pleased to still be in the field after all these years. I still get as excited about getting a new research grant or a new paper published as I did when I first started out as a researcher. I was lucky to have been one of the first people to work on the economics of social care and then on the economics of mental health, and I am pleased that I have been able to help shape both of those areas of research to some extent.

**Q Could you discuss a recent randomized controlled trial of interest that you have been involved with?**

I have been working on the DOMINO trial led by Rob Howard (Institute of Psychiatry, London, UK) and involving many of the top dementia researchers across the UK. This Medical Research Council-funded study has been looking at drug treatments for individuals with Alzheimer's disease, and, in particular, whether it is beneficial to carry on with drug treatment beyond the point that NICE currently recommends in its guidelines [101]. We compared patients who discontinue donepezil (as recommended by NICE guidelines once those individuals reach a particular stage of cognitive decline) with patients who continue it, switch to memantine, or switch to a combination of memantine and donepezil. The outcome results are very positive for the continuation of drug therapy, and this paper is already being heavily cited [1]. The economic results have not yet been peer-reviewed, but I can say that they are certainly interesting. Indeed, we are also getting some potentially important results from two other randomized trials in the dementia area, one looking at cognitive stimulation therapy and the other at a 'coping intervention' for carers. These should be in the public domain quite soon. It is great to be doing research that has the potential to change the way that people receive their care and treatment.

I am a big fan of NICE; I think they do a very good job with reviewing and synthesizing evidence from a wide range of sources in transparent and participative ways. They

do not always get it right, but no one ever does. I would say that the NICE guidelines we have for dementia care in England and Wales are as evidence-based as they could be, and the role of any self-respecting researcher must be to supply more and better evidence so that those guidelines can develop. Of course, it can take a long time to implement guidelines and to change practice 'on the ground' – the familiar 'implementation gap'.

**Q How successful are current methodologies used in dementia research? Are the end points often clinically relevant?**

The end points now being measured in dementia research have generally got much better because there is now more attention being paid to, for example, behavioral change and the alleviation of depressive symptoms. There is also more attention being paid to the quality of life expressed by the individual with dementia him/herself, and tools are now much better at enabling individuals to express their views. Therefore, the end points have got greater in number, broader in scope, and are beginning to explore the more personal experiences and views of individuals with dementia, and their family members and carers. This is a significant improvement, and has partly been driven by the way that services and decisions have (gradually) encouraged the greater involvement of people with dementia and their carers.

From the economic side, we are primarily concerned with exactly those same outcomes, but also with the cost of achieving them, comparing two or more therapies. In economics research, we would generally want to work with the same span of outcomes as in clinical research.

**Q What, in your opinion, is the most significant hindrance to better dementia care?**

Well I have to say it has to be money at the moment. Not just money, but money is certainly a problem in that we are quite often aware of good practices, good interventions and good strategies, but we do not have the resources available to implement them. Another hindrance is that for a lot

of individuals with dementia, their primary carers are either family members, or quite low paid social care or nursing assistants who do not necessarily have the right training to provide good quality, evidence-based care. We often know what works, and we sometimes even have the resources to put things into practice, but the staff do not necessarily have the training (or the time to engage in the training) to learn those skills. This implementation gap is the big challenge.

**Q To what extent are outcomes influenced by cost in dementia care research?**

In service terms, there are inevitably resource constraints; there always have been and there always will be, but they are now more obvious, more tangible and more challenging than they used to be given the global economic situation. It is good that dementia has a higher and, I think, better profile than previously: the general public are more aware of what dementia is and views on the illness are, I think, less negative. So I hope, as a consequence, that it is easier for dementia to fight its corner when it comes to resource allocation. In the UK, we are very fortunate that the government has put a lot of emphasis on dementia research as a platform to improve dementia care.

**Q How effective & cost effective are current support interventions for dementia caregivers?**

I am currently working on a project called START, which is led by Gill Livingston at University College London (London, UK). I mentioned this study earlier: it is an intervention delivered by psychology graduates who are trained to deliver a package of support, including psycho-education about dementia and associated behavioral problems, ways to reduce carer stress and relaxation. Carers get face-to-face training, a manual and a relaxation CD. The results are certainly encouraging, and there should be a publication quite soon. I can think of two or three other studies that are looking at better ways of supporting and training carers, and that have also proved cost effective. In fact, we recently reviewed all the

economic evidence in relation to dementia care and treatment, and you can see the details there [2]. Dementia care has always been primarily delivered by unpaid family carers, and finding effective and affordable ways to support them is crucial given the aging population and the economic crisis.

**Q With the aging population, are we financially prepared to cope with the increases in dementia cases?**

No is my basic answer. When projections are made for the aging population and the consequences of aging on costs in the health services and in social care, you can see that the cost of supporting older people and particularly those with dementia is going to increase rapidly over the coming decades. The proportion of our national income that is dedicated to dementia care is going to have to increase dramatically if we continue with current treatment and care arrangements, and it is not clear whether taxpayers are willing to pay higher taxes to support individuals at this stage in their lives, as tax increases do not win a lot of votes in political elections. In England, there was a report in 2011 by the economist Andrew Dilnot that made some very sensible recommendations for the financing of long-term care [102], but there has been no response yet from government. Indeed, successive governments have kicked this issue into the long grass and so – as a country – England remains poorly prepared for the demographic changes projected for the coming decades.

**Q From an economic perspective, what are the greatest challenges that need to be faced in the fields of dementia & other neurodegenerative diseases in the next 5–10 years? In your opinion, how should these be tackled?**

One challenge is to provide the right context and environment to enable families and other unpaid carers to continue to do what they do, which is to be the most important resource in the dementia field. Another challenge is that we have seen a move over the last 5–10 years to give individuals more control and more choice over their public services, and that has especially been the case in health and social care. I certainly

welcome this, but I think there are people in particularly difficult situations, for example, those with middle-to-late-stage dementia, for whom there are still too few opportunities to exercise much choice over key aspects of their lives. Of course, it is horribly difficult given the effects of dementia, but dementia patients are still not participating in key decisions in the way that many other patients and service users are now beginning to do. Therefore, trying to find ways to better engage patients with dementia so they feel they can play more of a role in key decisions in their lives is a challenge I would like to see us wrestle with a bit more.

#### Financial & competing interests disclosure

*M Knapp has no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria,*

*stock ownership or options, expert testimony, grants or patents received or pending, or royalties.*

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#### ■ Websites

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