

iris

Stimulating Thinking on dementia policy and practice from the Dementia Services Development Centre at the University of Stirling

06. Masterclass 2015

Dementia and politics

This Masterclass was put together to take a fresh look at dementia and politics. The idea was simply to bring together a small number of people from different backgrounds to reflect on how politics is shaping and reacting to dementia in the world today, as it grows more visible and prevalent worldwide.

This Iris is designed to accompany an audio recording of highlights from the discussion which is available on the Masterclass website www.dementiamc.net.

There is a lot of political interest in dementia at the moment. This is markedly different from 25 years ago when DSDC started. Dementia is now big politics – an explicit part of social and economic policies and increasingly part of popular discussion in the media and in everyday life. But are the right questions being asked? Are the political solutions up to the job? Are the issues dominating public discussion today really getting to grips with what is needed or simply getting in the way? Are we, whoever “we” means, storing up problems for the future?

What follows identifies some of the issues which are NOT being talked about, but should be. The analysis suggests there is real value in a more open and sophisticated political engagement with the implications of dementia than is currently happening and argues for more activism as a result.

Context

The Masterclass showed the range of ways dementia and politics interconnect. It is tempting to reduce politics to a set of issues for the state and government to wrestle with on our behalf, separated from local politics or domestic dynamics. This reflects a traditional division in the print media between national news, local news stories and features. These divisions are getting in the way of a political engagement with dementia which will genuinely face up to the importance of dementia now and in the future, which cuts across such neat boundaries. Politics generally is about what all of us do and how we act. In relation to dementia particularly it is clearly no longer about what the state will do.



In June 2015 DSDC held a special dinner and discussion to explore the relationship between dementia and politics. This Iris takes as its starting point some of the ideas explored at this Masterclass, held in London as part of the year-long Dementia Festival of Ideas, marking the 25th Anniversary of DSDC. The Centre, like the Masterclass, was made possible by the Dementia Services Development Trust which has generously supported DSDC since its inception.

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What is not being talked about

1 – Solutions to “the dementia problem” are only likely to be partial

Having dementia so heavily visible on the radar of governments creates a particular type of problem. It fuels the myth of a comprehensive, reassuring solution being just around the corner. There has to be one. Public confidence demands it and without public confidence elections are lost. This has contributed in the UK and other developed countries to a collective buy-in to the notion that government is able to galvanise and to deliver imminent solutions for dementia – a mix of investment in drug-seeking research, of increasing public knowledge (using the public health model of increasing understanding and changing behaviour) and in overhauling the way the system of health and care works. Together these elements are now established as the G8 standard narrative of what needs to be done, with scientific, celebrity and charity endorsements. The only problem is that this is going largely unchallenged in spite of the absence of any evidence these are the most effective ways of engaging with dementia or any clarity on expected impact. It is becoming increasingly difficult or unwise to challenge as the juggernaut rolls on. *How can one engage critically with something which says it has all the answers and which has bought off critical thinking?*

2 – The big demographic numbers are a problem

The charitable sector and the state are largely responsible for promoting the apocalyptic view of dementia – by projecting sharply escalating prevalence numbers into the distant future. For the advocacy organisations this is fair enough as a tactic to raise profile and funds, but governments and researchers should have been challenging the assumptions. However even as the big numbers have not been borne out – the straight line projection has been known for years to be a flattening curve – no adjustments have been made. The big numbers have done their work and still provide a plank of the dementia narrative – the sheer scale of what we face, the tsunami of make-up-the-figure people with dementia by make-up-the-year. This narrative is a problem. The big numbers disable rather than enable. They distract and can even be used to distract from things that can be and need to be done now. They shift the debate from older people today to older people as a problem in the future. It becomes about scaling up services to cope in future and limits the political debate largely to the need to find resources. For the public the big numbers contribute to the overall tone of fear and helplessness about dementia, and it is not really about us now but about us in future. Looked at positively the big numbers are presented as meaning “we must act” and in a big way. *Is it too late to create a more positive narrative based on action which will improve the lives of people now?*

3 – The media framing of dementia is damaging people

People seem willing to accept that the media promote a narrow range of issues which together shape how we see dementia. This is explored in the blog site [DIAMetric](#). What is not being discussed is how much it actually matters, how damaging it is. We all need something positive to say; a line on dementia. The mixture of stories of hope, of individual courage, of miracle cures and dietary advice, of celebrity impact and endorsements are what you would expect. The damage is twofold – not only is this coverage manipulative and shallow but it also occupies the space available for dementia with its shallowness. It prevents more nuanced discussion of what dementia means now and in future. It creates a form of political consensus about what matters – one that focuses largely on the wrong things. *So what do we do to challenge the lazy and dangerous media lines on dementia?*



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4 – The charity sector is compromised

The role of charitable bodies has shifted in the last decade as dementia and ageing have gained more attention. At its most crude the advocacy bodies have in effect become an extension of government, happy to legitimise policy in return for access to funding. This is a dangerous game. Leaders of charities and civil servants share platforms celebrating the unproven success of their policies without any objective assessment of impact. Charities may well have a continuing role in the future but they should not be relied upon in the way national and local government currently do. It remains to be seen whether the advocacy bodies can recover credibility and remain in business, as both state funding and donated funds become much harder to come by. *What are the important agencies for the future? What are the real prospects of communities and families filling the gaps left by a shrinking state and a compromised charitable sector? How can something new be brought forward to replace the old?*

5 – “Not enough resources” is a Catch 22 which needs to be broken

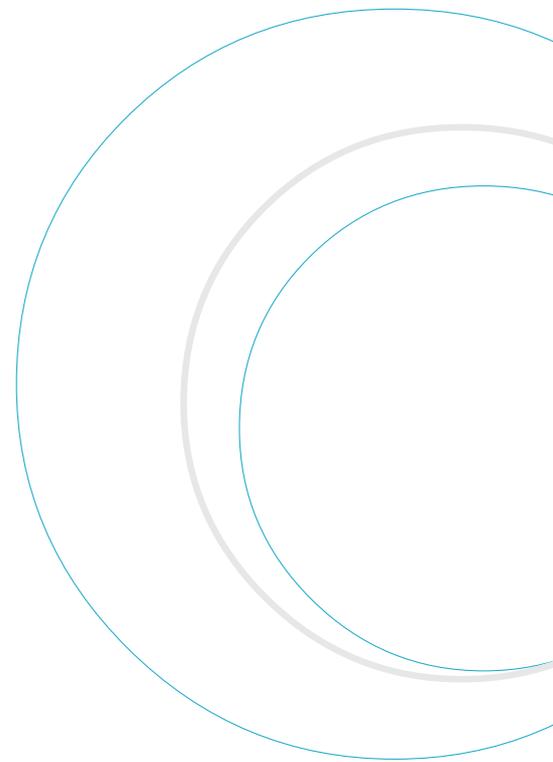
No politician seeking power can afford to admit that there will not be enough resources to meet future demand for long-term conditions, including dementia. To do so would imply the government is in fact not in control of its brief, that the system is broken and they are incapable of governing. It would also fly in the face of a core narrative about eternal economic growth, continuous social growth and permanent health improvement which people in the affluent West have been brought up to expect their politicians to deliver. *Can these various dynamics and myths be disentangled to allow an honest engagement with what is sustainable – a new deal which will see us into the future?*

6 – Dementia is about hard economics as much as social values

By repetition the notion that there are strong economic reasons for addressing dementia has gained ground in recent years. It remains the most likely argument to unlock political thinking given the importance of “the Economy” in Western economies. But beyond the general principles of crude cost benefit analysis, the work to make this case work in favour of people with dementia remains elusive. Where resources should be invested to create maximum value and the political will to pull this off will remain unclear unless work is done on the detail. Dementia is an ideal subject for such analysis. It may well be the issue which allows a fresh look at the economic and social implications of increasing longevity and health. Dementia certainly needs to be positioned critically in the context of the forces of wider social and economics of health and wealth creation. This work, probably best done away from Government, will very likely challenge the current framing of dementia in the media, politics and public health. *Who is going to pay for the work and who will listen once it has been done?*

7 – Drugs can only offer false hope

Investment in pharmaceutical development is a decent option if the intention is simply to postpone the progress of dementia in some people, possibly. But there remains, in spite of recent announcements, no real prospect of a cure for the underlying diseases which cause dementia in people. It is no nearer today than a decade ago. The drug solution is irrelevant to everyone with dementia or with the prospect of dementia in the foreseeable future. The politics here are around positive news stories and political complicity with them. Who can stand up and deny the myth of progress and the need for the pharmaceutical industry to gain even more investment if the prize is a solution to the problem of dementia? Someone has to, because not to do so perpetuates the cruelty of the drug solution for people with dementia and those who care for them. The search for the miracle cure also takes the pressure off serious investment in initiatives which can improve the lives of people with dementia today. Acting on what we know works today is not just a better use of resources, it cuts through the narratives of false hope and fear and can deliver real improvement to lives. *Who will counter the drug myths and how can this be done?*



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8 – Old ways of working will not deliver what is needed

It could be argued that this IS being discussed publicly, but the majority of debate is still about changes to the system itself. The boundaries between state and personal responsibilities are being redefined on the back of reduced funding. However fundamental issues about responsibility for care of people with dementia in future are lost in the anecdotes of blocked beds, failing community services and overrun unscheduled care. This is a world of care pathways and arguments for increasing staffing levels. Little modelling of numbers. Less objective assessment of choices to be made and how they might be made. No public engagement with a set of future scenarios which reflect a very different world where who does what will need to be different. As with drugs innovation is most likely to come by making more of the hospital function happen in the community with the community acquiring much greater confidence and specialist knowledge around dementia. *How can the focus be shifted from largely being about changing the system to equipping more people with the knowledge they need?*

9 – The limits of Involvement

“Involving people with dementia” is now a requirement for anything which includes the word dementia in its title. It is inadvisable, and may even be impossible, to raise any concerns about the real value of such involvement. It is even difficult to raise any concerns about tokenism and professional roles in the process of co-production where dementia is concerned. Who are you, even as a professional, to question the lived experience of someone with dementia? And who still feels able to question the views of representative bodies who claim they can draw on a collective voice when they are promoting their own self-interests as fund-raisers and service-providers? The concern is not about the value of involvement, but about how issues involvement brings with it are handled. Any involvement must not be at the expense of other expertise. It is not good enough to run the risk of professionals with real evidence-based learning and knowledge being “trumped” by a carer or person with dementia who, though very experienced, only has their own individual experience, perhaps of only one person, in one health care system, from one social background, to go on. *So how can professional and public voices be brought together as effectively as possible?*

10 – Dementia is a feminist issue

Women are more affected by dementia than men across the world. This is in part a consequence of the inequalities and problems thrown up by the notion of care, and by the social and economic problems caused by the way care is seen, supported and rewarded in different societies. In many ways dementia is a largely “undiscovered” feminist issue. Age yes, but dementia not yet. The “voice” of dementia is still largely limited to that of the “expert by experience” (where voices are validated by professional invitation). There is no room here for the disruptive perspective which sexual politics can bring. In spite of its intergenerational impact dementia has also not yet become an issue which has the power to prompt women of all ages into more challenge and greater activism, as other issues have in the last decade. Dementia seen as a feminist issue however may have real potential to change how dementia is seen and engaged with. *How can dementia emerge as a much more important feminist issue?*

11 – Dementia friendly communities need to become less bland and more political

The adoption of the concept of dementia-friendly communities and all things dementia-friendly has become a huge industry, backed in the UK by badges, standards, awards – the works. It is noticeable that this idea, imported from Japan, has no clear underpinning philosophy beyond a vague notion of what communities should be like. Dementia-friendly communities have got wings by being part of the package of solutions endorsed by the state. They are rarely a spontaneous or genuine response by families and communities themselves.



The idea has worked in the UK most effectively where it fits with established notions of asset-based community development, but even here there is a dependency on institutional stakeholders and short-term funding. As the austerity agenda has become more prevalent in the UK dementia-friendly communities are becoming a way of gathering local forces to cover the cracks in provision and thinking. Where they are done well they can provide some short-term focus on practical change. But there is no evidence that dementia-friendly communities are becoming vehicles for more active, political change. Why would they be, given their origins as part of a government/state-backed charities programme? They are acting as sticking-plasters for reduced state resources or fulfilling small-scale local aspirations. *But could they also provide a focus for what is not being discussed? Could dementia-friendly communities emerge as a vehicle for disruptive and sustainable change?*

12 – Euthanasia is in fact not a problem

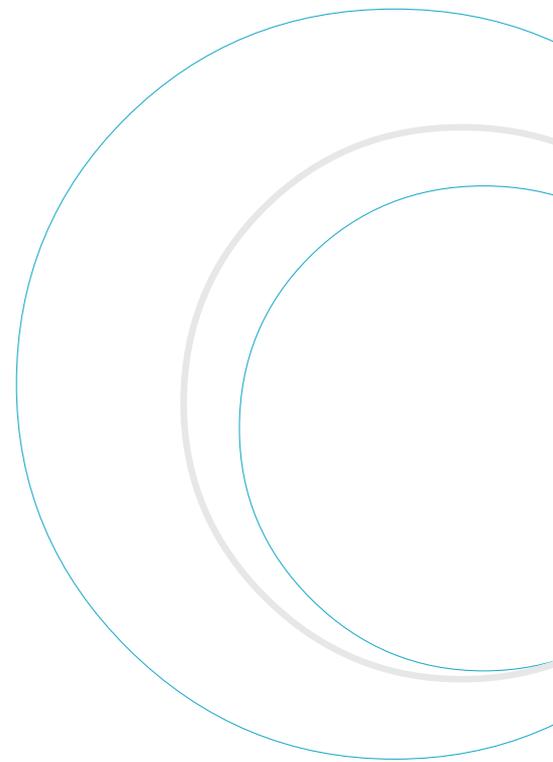
Euthanasia is currently presented as an issue in the media largely about freedom to choose and a reflection of fears about a dreaded decline. “What would you do?” “Do you agree?” Celebrities give their opinions. Experts exchange opinions. Euthanasia is however no more a helpful way of thinking about dementia than to speculate about the impact of the overdue pandemic. The euthanasia issue does provide an opportunity to address directly what people feel as individuals, to engage with what they need or want to know to regain control over something they see as out of their control – the inevitable decline caused by dementia. *Can euthanasia become more about knowledge to regain control and less about some form of escape?*

13 – Dementia is a human rights issue

This is a hugely underdeveloped area. There is some discussion within hospital and care settings of ethical issues that arise in relation to care of older people, but there has not yet been a sustained attempt to address dementia in respect of existing human rights legislation. Rights go beyond the political control of countries. This is potentially a powerful way of opening up a new discussion about what the state provides and how the rights of people with dementia are being met in different countries, referring to already-established principles. It would be important to make sure that the focus on human rights was, like euthanasia, about fundamental principles and positive change at an individual as well as at institutional level. But the hope would be this would provide a new way of encouraging a confident advocacy for what people should reasonably expect, its limits and what else needs to happen to meet needs.

14 – The need for activism

The issues raised so far suggest things need to change. Dementia is more visible than it has ever been in the West. This does not mean that the right policies are being pursued or the right thinking is being developed. Nor does this mean resources are going to the things that will make the most positive difference to people’s lives. It is not good enough to say this visibility is inherently a good thing simply because it counters stigma and draws attention. That era is over. We have to address a more complex situation where a lot is happening but these are not really things which will make a difference in any evidence-based way. More worryingly many things for which there is sound evidence is not being done. The current focus on dementia might be seen as no more than a sophisticated version of “anything is better than nothing”. The world of dementia is crowded with people doing things. There appears to be a lot going on. But what is needed is a type of activism which opens dementia up, pursues difficult questions about efficacy and impact of what is going on and secures a shift in thinking and doing.



Many things for which there is sound evidence is not being done. The current focus on dementia might be seen as no more than a sophisticated version of “anything is better than nothing”.

Put simply this activism is about

- acting today on what we know makes a difference to people's lives
- making the hard social and economic case for dementia wherever it needs to be made
- challenging the current framing of dementia in the media and politics - creating a new narrative for dementia which goes beyond the superficial or the politically expedient
- what people need to know and do both now and in future, and how they can change things as well as accept them
- mitigating the hopeless hunt for a single set of solutions by the state
- disrupting current thinking and promoting the need for wider use of evidence and research
- creating conditions where people are clear about what they can expect from whom

This activism needs to be seen as a new disruptive voice. It needs a new vehicle, somewhere international to gather evidence and to collaborate and then to support decisive action. It is not so much about campaigning for change by the state or by others but about offering an alternative to them. This is what DSDC will seek to do in the next 25 years, working with whoever shares this view and can make change happen.

In the end dementia care and the future for people with dementia is about what we do – us, our friends and families.

Mark Butler would like to thank those who took part in the MasterClass on which this iris draws:

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Harry Cayton – *Chief Executive, Professional Standards Authority*

Jane Salvage – *Independent Health Consultant*

Dr Claire Nichol – *Consultant Geriatrician, Addenbrookes Hospital Cambridge*

Professor June Andrews – *Director Dementia Services Development Centre*

Professor Allan House – *Professor of Liaison Psychiatry, Leeds Institute of Health Sciences*

Johan Vo – *Deputy Chief Executive, Alzheimer's Disease International*

For more information visit:

Dementia Festival of Ideas www.festivalofideas.org.uk

Masterclasses www.dementiamc.net

Dementia Services Development Centre <http://dementia.stir.ac.uk/>

The Dementia Services Development Centre (DSDC) exists to improve services for people with dementia and their carers throughout the UK and beyond. We do this through research and teaching and by supporting workers and organisations that provide care for people with dementia.

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