

International Perspectives

Promoting Person-Centered Care for People with Advanced Dementia

An Interview with Mary Marshall, OBE, Director Dementia Services Development Centre University of Stirling, Scotland

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[Professor Mary T. Marshall, OBE](#) has worked to improve the care of older people for more than 25 years, as a social worker, lecturer, researcher and manager of voluntary organizations. In the following interview, she provides perspective on the care of people with advanced dementia from her vantagepoint at the helm of the [Dementia Services Development Centre](#) (DSDC) at the University of Stirling, Scotland, an internationally renowned center for dementia research, training and service development. The DSDC was one of the partner organizations in [EACH, the European Alzheimer Clearing House](#), which was set up to identify and disseminate expertise and good practices in dementia care from throughout Europe.

What can you tell us about your organization's efforts to improve dementia care in Scotland?

The Dementia Services Development Centre is an organization which exists to extend and improve services for people with dementia and their carers by providing information, training, research and development consultancy. Although we do not operate directly with caregivers, the Centre provides advice, contacts, information, and consulting to any person or organization setting up or improving services.

The philosophy of the DSDC, reflected in all of our activities, is to promote more person-centered care of people with dementia. Person-centered care is based on the idea that until recently, most people with dementia have been surrounded by a malignant social psychology, which damaged them as much or more than the actual brain damage. Changing those attitudes and the social built environment are two things that you can do a great deal about and, if you can get them right, you can really benefit people with dementia.

In most developed countries of the world, in which the population of elderly people has increased enormously in this century, dementia care is an area for which there are high and increasing demands, combined with fairly low levels of expertise, or only recently emerging expertise. Our Centre was started ten years ago by a campaigning group called Scottish Action on Dementia to address this need for information, training and sharing of expertise. When we started, we were the only such center. There are now six or eight organizations like us—one in Australia, one in Oslo, one

in Dublin, and the rest elsewhere in the United Kingdom.

Although DSDC only serves Scotland, we became "European" when in 1995 we partnered with the European project, EACH, which stands for the European Alzheimer Clearing House. EACH was started by a very eminent Belgian physician, Dr. Franz Baro, to be a resource of information and expertise for Europe. It was initially funded through some money for dementia research and information dissemination that was briefly made available under the public health policy directorship, DG5 (Directorship General 5) of the European Community. The EACH projects were incredibly diverse, including a focus on economic factors, ethical factors, and helping caregivers to sustain their care. Our Centre participated in some of the start-up projects, including researching good practice in dementia care in European countries.¹

Since 1997, when the EACH projects were completed, the whole dementia movement in Europe has become much more dynamic. There was a huge Alzheimer's Europe conference in London this July (1999), attended by more than 700 people. Alzheimer's Europe is now very well established and very energetic, and has all kinds of projects.

Where in Europe do you see the greatest improvements being made in the care of people with dementia?

In Scandinavia. I think the investment in staff training, staff development and new models is very considerable in all the Scandinavian countries, and it's quite remarkable. For example, small domestic models of care, which are highly person-centered, are the norm in Sweden, and increasingly the norm in Finland. I would also include Denmark and the Netherlands as areas where there are a lot of very high quality developments, and constant improvement. I'm not saying it's all good. I've seen some rubbish, too, but it is remarkable what they're achieving.

What accounts for their success?

I think it must be investment. They're smallish countries, and they decide a priority and go for it. Finland and Sweden are fairly centralized, and if the central government decides it's going to happen, chances are that it will. So they have humane policies that start at the top and are energetically promoted.

In Finland, for example, the Center for Research and Development in Welfare and Health, (acronym STAKES in Finnish), located in Helsinki, is a government research and development unit. They've done brilliant development work in dementia care. Annikki Korhonen, a really remarkable lady, is the civil servant who's been identified to develop dementia care in Finland.

They have applied the small, domestic care model and have undertaken a whole set of other initiatives to make dementia care more person-centered. They have very good day care, for example, and ever increasingly home care. The startling thing about Finland's experience is that it's all so quick. Seven or eight years ago, they favored a traditional big nursing home, bulk care model. But having decided to change it, they moved fast.

How would you compare progress in the British Isles and, in particular, Scotland to what Finland has been able to accomplish?

The United Kingdom is a much bigger country, and there's much less of a steer from the top, and much less investment. Nevertheless, I feel very optimistic about what's been achieved. I've been director of DSDC for ten years, and the greater understanding of what can be achieved by improving the social and built environment is truly formidable. I think everyone now knows that the

small domestic model is the right one, but whether they feel they can economically provide it is an issue. They can no longer say they don't know about it.

Also, there is a much greater appreciation for what can be accomplished through person-centered care, in part because we and others have been hammering home the point for ten years. But much more importantly, because people have been able to see what can be achieved with person-centered care. They can see people responding to highly-individualized care in the way that they wouldn't have believed. If you start modifying the social and the built environment to tailor them to the individual you can sometimes actually see *re-mentia*, diminishing dementia. You can often see a leveling out of the deterioration.

There are still some totally dreadful services in Scotland, but I think even they are aware of the potential for change and are eager to achieve it. We've had a burgeoning of very big nursing homes, and some of those have dementia units, but the units are far too big. The standard unit size is 30 beds, generally in clusters of maybe three of those units. However, I think that even the biggest nursing home company these days would say it knows it ought to do 10-bed dementia units, it just doesn't feel able to do it. I don't think there's anyone defending 30-bed units for people with dementia. I don't want to tar them all with the same brush, however, because some of the private companies are providing the best small-scale clusters.

What is the primary setting for dementia care in European countries?

Although quite a lot of people have to be in some sort of institutional setting, the priority of all European countries is keeping people at home. There was a very interesting project based in the University of Glamorgan in Wales, called ETAS (European Transnational Alzheimer's Study), which looked at social and health policies in dementia throughout Europe and identified five themes which applied to all European countries, and four which applied to most. Keeping people at home and supporting carers to keep people at home were the top two themes in social and health policy related to dementia in every single European country. But the figures for the prevalence of dementia in Europe and the location of care are tricky because there's a very substantial number of people with dementia who haven't had a diagnosis.

There's no doubt that British policy is very clearly about keeping people at home. In reality, however, that hasn't been borne out in practice, because it's often cheaper to keep people in these large places. We've closed down a lot of our National Health Service long-stay provision, which has on the whole been replaced by private, for-profit nursing home care, rather than home care. But the momentum is in favor of home care.

What kind of support is needed to provide good dementia care at home? And what kind of support do family caregivers tend to receive?

It's hugely variable, because it depends on the carers' capacity and health, and the living environment. I'm very optimistic that some of the technologies that are increasingly available will lift the burden on carers a bit. If you get a package of home care, it can be all kinds of combinations. It could be day care five days a week, it might be home visiting or home respite service. One of things about the UK is it's a post code [zip code] lottery. It absolutely depends on where you live, because it depends fundamentally on the local authority (and the available skills, commitment, and budget), which organizes home-care packages.

In some areas that might mean properly-planned 24-hour care with a combination of health, social work, voluntary and informal care by relatives and friends, properly packaged up into a fairly

satisfactory mix of services. In other places, it might be a little bit of day care and the odd district nurse. It's very, very hard to generalize, and that, I think, is characteristic insofar as there is no minimum standard or national criteria for eligibility for anything. The same generalization could be made about provision of palliative care at home.

Given the push to care for people with dementia at home, what provision is made to assist the family during the advanced and terminal stages of the disease?

Most people die in hospital; it seems to have become a pattern. If you want someone to die at home, no one's going to object, they will support you. But that isn't the norm. In the United Kingdom, family caring at home for someone who's in the terminal stages of dementia would receive help from a combination of health care providers, including the general practitioner, the Home Nursing Service, the Social Work department, providing both equipment and staff, and what we call MacMillan Nurses, who provide short-term care for people who are dying at home. They are often used to provide pain management and overnight care, giving carers a break at night.

To what extent is hospice care available for people with dementia in Britain?

The interesting thing, I think, about the British hospice movement is that it's only now beginning to think about dementia. We at DSDC have been extending the hand of friendship to hospices for about three years. We have the impression that they occasionally had someone who's dying of cancer who did either have dementia or get dementia, but this was not a key issue. Up until now, hospices have overwhelmingly cared for people with cancer. But now the hospices are becoming more and more interested in dementia care, in part because there are more and more hospices, partly because they're managing people with cancer at home more effectively, and partly because hospitals are managing these patients better. So, hospices are expanding their idea of whom they can serve. I was invited, for example, to chair the hospice social workers' conference the year before last to stimulate some more thinking about dementia, and for the first time, one of my colleagues who is our specialist [in terminal dementia care] was asked to speak.

DSDC has done a literature review and key-actor interviews on terminal care and dementia. As a result of this work we got more money to develop a training course with our colleagues in Scottish hospices. The training consists of a five-half-day course, which will start this autumn. If it's successful, we would hope both to repeat it and to turn it into training material to disseminate more widely.

What about links between hospice or palliative care and dementia care in other European countries?

There are ever increasingly satisfactory and mutually fruitful links being developed between people involved in dementia care and those in hospice or palliative care, but I don't know the extent of it in Europe. It didn't come up in the research we did for EACH. We didn't ask about end-of-life care specifically, but it also didn't come up spontaneously.

I suspect the reasons for this vary in different parts of Europe. I think the idea of dementia services is not well-developed in much of Europe. In Southern Europe, for example, it's still very much considered to be a family problem. The amount of input provided, both by the voluntary and the statutory sectors, is pretty small. In those regions they are beginning to awaken to the need to support family care, but it's still not well developed.

What needs to be done in European countries to ensure good end-of-life care for people

with dementia?

There are two assumptions that affect dementia care near the end of life. One is that poor quality of life is necessarily part of dementia, and the second is that people with dementia don't always need active palliative care. There are dangers in these attitudes.

A major barrier to good care near the end of life is the belief that because a proportion of the brain is not functioning, therefore feelings, both emotional and sensory, are not functioning; spirits are not functioning. There's an assumption, I think, of much greater levels of lack of awareness and lack of sensation than there's any evidence for. People with dementia, especially in the later stages, are often seen as some other species without normal feelings. So, staff caring for people with dementia may be unaware of or may not believe that dementia patients can benefit from all the important principles that we have in palliative care and the idea that there can be quality in end-of-life experiences.

Moreover, because people with dementia can't tell you that they're in pain, there's only very slowly beginning to be any interest in pain and dementia. There was a literature review on pain and dementia in the last edition of *The International Journal of Geriatric Psychiatry*, which didn't find a great deal of literature on this.² However, this article indicates that although pain management in people with dementia isn't always even considered or assessed, there is now a general raising of interest in the topic.

Based on our own small amount of research, our view is that there is a big need to counter the prevailing idea that people with dementia have no feelings of awareness of death or need for comfort and continuity. I think that a person-centered, more optimistic view of dementia care is still undiscovered in quite a lot of parts of Europe.

Our view is that where you get good dementia care, you get good palliative care because you get staff who see the person, as well as the illness. Sylvia Cox, a planning consultant here at our Centre, who has done some research in this area, believes that the one seems to follow the other—if staff are good at dementia care and person-centered care, then they're much more likely to have a more sensitive and positive approach to palliative care. You also need to get people used to thinking that people with dementia need both health and social care working together.

Does it work the other way as well? If an institution or staff are providing high quality palliative care in general, is it more likely that they would provide person-centered care to people with dementia?

I think it would be less certain, because what you often get in places which haven't got a real grasp of dementia care is this assumption that these people's brains are shot. That their awareness and sensitivity and feelings are gone. I worked once in a truly appalling psycho-geriatric unit where staff used to say to me, "Isn't it just as well that the patients don't have any awareness of where they are and what's going on?" I think that is still an approach in quite a lot of places where the staff do not understand that people with dementia can feel to the end. And that awareness of death is not necessarily something that goes in a person with dementia.

I visited a day center for people with dementia in Australia where the main day-to-day subject of conversation was death. They knew they were dying and the organizer of the day center appreciated that they were preoccupied with that fact, so, she encouraged that kind of conversation. Her view was that in most places, staff don't have that conversation with people with dementia because staff can't cope with it.

I also visited a very good care-housing unit in Norway which faced a cemetery, and I asked, "Is that really a good idea?" and was told, "Yes, it stimulates really important conversations whenever there's a funeral." But I think that's much more about the staff's ability to respond and not deflect that preoccupation than it is about the particular location, really.

Another interesting thing—and this is just an observation based on anecdote—is how often relatives will talk about moments of lucidity in their loved one around the time of dying. There is a curious phenomenon in dementia. It seems that even the most disabled person can sometimes have a moment of absolute lucidity when the synapses sort of click. I've had numerous carers talk to me about that happening on the deathbed. I don't know that there's any hard evidence of that at all, but it is an interesting observation, isn't it? Astrid Norberg, a very eminent dementia expert in Sweden, has talked about how such moments undermine a lot of our preconceptions about dementia.

Is there much advance care planning in the United Kingdom for people with dementia?

It's very, very unusual in the UK to see tubes and drips in any facility caring for people with dementia, so I suspect that people are dying earlier. Certainly, we do get visits occasionally from people managing facilities in the United States, and they talk about a lot more interventionist treatment for very old people than we would expect to have here. Some people here do have advance directives, but that's very unusual and only in a small minority of the population. Generally speaking, people with dementia who had some kind of acute episode in a hospital ward would not have a radical intervention. My father, for example, got pneumonia, and was allowed to die comfortably. Unless anyone had a very strong objection, I think that in general, people in such circumstances would be allowed to die. So there wouldn't be a plan, as such, there would be an understanding with the physician.

The perhaps more worrying side of that approach (which I think is, on the whole, humane and proper) is that often assumptions are made about quality of life in people with dementia. "Oh they've got dementia, so we don't need to do X and Y." People might not get surgery they require, to remove a bowel obstruction, for example, simply because they have dementia. I get the impression from talking to some carers and staff in the field, that often someone with dementia in their care has a good quality of life, and is actually quite enjoying themselves. Yet, if the person is hospitalized, the acute-hospital sector makes assumptions that dementia equals poor quality of life, and acts on that basis. I think that sort of discriminatory allocation of health service resources is a bit of a worry in the situation in Britain where the Health Service is under a huge strain resource-wise. In a sense, that's more of a worry than our willingness to allow people to die comfortably before they've needed tubes and drips.

In the United Kingdom, what efforts are being made to maintain connections and communication with people with advanced dementia?

The big question is, when are people *not* able to communicate in some way or other? The skill that we have to learn is how to communicate with people who have lost verbal communication skills, and not assume they can't communicate. In his novel *Scar Tissue*, which is clearly based on a real life experience, Michael Ignatieff, who is Canadian, took the view that his mother, who had dementia, was still a whole person inside and the problem was his that he couldn't communicate, not hers, that she wasn't there.³

There has been an enormous burgeoning of interest in the UK in communication in dementia. We're moving very swiftly to a much greater understanding of the language of people with dementia, who often use metaphor and stories to share their views and fears. We have a research project which

is looking at a whole set of new skills in how you elicit the remaining language, and also how you interpret non-verbal communication and facilitate that. I think that this type of research will have a major impact, once the skills are disseminated.

At DSDC, we've identified communication as one of the areas we want to specialize in and have two ongoing communication projects. Three or four years ago, we produced a substantial British text, called *Hearing the Voice of People with Dementia*, by Malcolm Goldsmith.⁴ We've built on that a couple of projects. One is on using the arts to communicate. The other is on a whole set of techniques, including using pictures and typewriters, interpreting behavior and discourse analysis. That links with very interesting developments in counseling people with dementia and psychotherapy in people with dementia. Some of our work is about people with dementia being more active participants in their care generally, commenting on it, making choices, having preferences. And that's very current in the UK because we're aiming for a more consumer-focused model of service provision.

Are you able to educate the family about this as well as staff?

Yes. We produced a set of basic training materials for families. We're now in an exploratory phase, looking at a whole lot of new techniques. We're not alone. There is really a huge amount of interest in it throughout the United Kingdom.

Please tell us about your project using the arts in communicating with people with dementia.

We employ a poet, John Killick, who has spent the last five to six years as a writer-in-residence for a major nursing home company. He takes down the voices of people with dementia literally, and edits what they say as poetry. His view is that people with dementia are natural poets, because they think in pictures and metaphors. And he has now started to work with us, looking at a wider range of the arts. He is collecting information on existing projects, such as those that use dance and drama, and also initiating some very small projects in areas where he doesn't think there is work going on.

One of the new projects that he has set up is about giving cameras to people with dementia residing in a nursing home, seeing what they photograph, and seeing whether taking pictures is helpful to people in their efforts to communicate. He's also got a mime artist working in a nursing home to see if gesture is something that remains when other communication capacities go. So there'll be a whole set of books arising out of that suite of small projects. He's writing up some of these projects now. Ultimately some training materials may be developed based on these projects, if there seem to be threads that run through that are useful to share.

Another colleague at DSDC, Kate Allen, is a clinical psychologist researching the effectiveness of a set of techniques to promote one-to-one communication and verbal communication with people with dementia. One technique she uses is to give someone a picture of someone else and say, "What do you think X thinks?" as a way of eliciting an opinion which they're not able to give you about themselves. Another technique she is trying is using boards on which photographs and other images are placed, to which the person can point. This is a well-established communication technique with people with severe injuries who can't speak. She's also looking at discourse analysis and at interpreting behavior.

Which health care professionals would be most likely to use these communication skills?

They're mainly staff running units where people live, nurses and residential staff of care housing,

long-stay hospital wards, nursing homes, residential homes. There's also some work going on in a day center, but most of it is where people are providing 24-hour care.

Is DSDC linked with any clinical settings officially?

Not formally. But informally, constantly. Kate Allen is working in about ten settings, in which the staff are serving as action researchers. She trains the staff to identify patients or residents and to try different techniques with them. They then provide her with feed back. She's so closely involved, she's almost part of it. But she doesn't want to do the work with the residents herself, because she wants to know that ordinary staff can do it. She's a highly-skilled, very experienced clinical psychologist, so what she can do is not replicable. We want techniques that are usable by front-line staff.

Will these projects in any way inform the development of your palliative care curriculum?

Everything gets linked here. It's like a stew, because it's a very small group of people (twelve staff) that know each other well and influence one another's thinking. And we have a sister organization at the University of Stirling, called the Centre for Social Research and Dementia, which is directed by Dr. Murna Downs. So we're very lucky in having very strong researchers alongside, who can undertake much bigger projects than we can.

Any closing thoughts?

I think the closing remarks are where you start from, which is that the two worlds of dementia care and end-of-life care have so much to offer each other. The exchange of ideas and closer collaboration will benefit both hugely.

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