



MARY MARSHALL
Director of the Dementia Services
Development Centre,
University of Stirling

An eFestschrift

PSSRU

Personal Social Services Research Unit

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Mary Marshall eFestschrift

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Dr. Andrew Fairbairn is Medical Director in the Newcastle, North Tyneside and Northumberland Mental Health Trust.

Professor Jane Gilliard is a member of the Department of Health Change Agent Team, part of the Care Services Improvement Partnership.

Jim Jackson is Chief Executive, Alzheimer Scotland.

Dr. David Jolley is part-retired but still contributes to clinical sessions in Wolverhampton as well as being involved in the DSDC West Midlands, Dementia Plus.

John Killick is Associate Research Fellow in Communication through the Arts at the DSDC, University of Stirling.

Baroness Murphy of Aldgate [Elaine Murphy] is Chairman of the North East London Strategic Health Authority.

Dr. Duncan Sim is Senior Lecturer and Head of the Department of Applied Social Science at the University of Stirling.

Pat Smith is now retired and was a Social Worker in South Manchester after several years experience alongside Dr. Felix Post at the Bethlem Hospital in South London.

INTRODUCTION

The development of dementia care services acquired a new impetus with the foundation of the Dementia Services Development Centre at the University of Stirling. From that time in the late 1980s, with the work of Mary Marshall at Stirling and others such as the late Tom Kitwood, it was possible to sense a new and more positive environment for staff working in this field, giving a sense of possibility where there was once mainly despair and anguish.

The occasion of the retirement of Mary Marshall from the Directorship of the DSDC at Stirling has led us to bring together these tributes and thoughts about her work. The contributors come from a wide range of backgrounds, key figures in old age medicine, people from the voluntary sector, universities, dementia centres and indeed some colleagues who worked with Mary at the University of Stirling. A common theme of these comments is her tireless energy and commitment coupled with a generosity both of spirit and of her own time in assisting others to progress dementia care in their localities. It is an impressive legacy.

This document is an electronic Festschrift, a celebration of the work of Mary Marshall and her contribution to the development of services for people with dementia. Services for people with dementia in the early years of the 21st century can look forward with greater confidence to providing the support that people and their carers need due to the work of Mary Marshall. This collection of perspectives honours that work.

We are grateful to our colleagues Judith Dennis and Alison McQuade who have organised the material.

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MARY MARSHALL



MARY MARSHALL OBE: AN APPRECIATION

Elaine Murphy

Mary Marshall retired at the end of August 2005 from her Chair at the University of Stirling after a life's work devoted to improving dementia care services. Her major contribution has been to champion the right of older people with dementia to be regarded as having partially remediable disabilities, rather than is so often the case, a jumble of irreversible cerebral incompetencies. The point of Mary's work has always been to promote the optimum functioning of the individual by reducing the handicap of impaired concentration, altered perception and cognitive deficits. As a consequence she has taught that it is crucial to develop a style of social work with patients and their families which emphasises the respect for the individual's past and current skills and aptitudes. This means thinking differently about what is necessary in the built environment and staff skills to provide really good care.

Most of us now take for granted that the physical and emotional environment in which care is provided should be designed to be prosthetic for the specific impairments of people with dementia. And what's more, that you can make or break a person's ability to function as a sentient social being by getting the environment right. We forget that twenty five years or so ago, few wrote about these things. It was considered quite acceptable to house long stay patients in Nightingale wards if they were made homely enough; serious research in this area was negligible. It is a lasting tribute to Mary that she and her unit have established an international reputation on the social care of people with dementia around this core theme. And it is the success with which social care is delivered that is going to make the biggest difference to patients and their families for many years to come, whether or not efficacious drugs evolve.

Mary's approach to the social care of people with dementia has underpinned her lasting legacy, the Dementia Services Development Centre at Stirling, established in 1989, the first initiative of this kind in the UK and now a highly

successful and much copied model for research and development in the field. The Centre has since won international recognition as a centre for excellence in the field of dementia care. In recent years DSDCs have been established in Oxford, Bristol, Newcastle, Manchester, Wolverhampton, Canterbury, Dublin and London and Wales but Stirling was first and remains one of the most highly regarded. Since the late spring of 2002, the Centre has been housed in the landmark Iris Murdoch Building, named of course for the novelist. The building is designed to compensate for the five disabilities experienced by people with dementia: impaired memory, impaired learning, impaired reasoning, high levels of stress, increased dependency on the senses. The use of colour, signage, layout, noise control and visual cues all promote a dementia friendly building. The Centre achieves its aim by offering dementia care practitioners, managers and planners development and planning consultancy, training, advice and information, evaluative and qualitative research and access to low cost publications, videos and audio material.

It is as well to remind ourselves that while DSDCs may now be an accepted 'good thing' in promoting local service development and a location for training and education, there was precious little support for the idea of such a centre when it was first mooted. Many universities turned down approaches on the spurious basis that if these units were about R&D there would be 'too much D and not enough R'. How wrong Mary has proved these doubters to be. The research output at Stirling has been of high quality, concentrating on the pragmatic and practical as a result of the Centre's culture and positive philosophy. When Mary retires, she leaves behind her a thriving centre and a talented group of people to carry on the work, numerous academic publications and text books and a field much the richer for having her work in it.

So how did all this begin? After her first degree at Edinburgh, Mary headed south to LSE for their classic Diploma in Social Administration and completed further social work training at Liverpool University and then Queen Margaret University College in Edinburgh. After several years as a front line social worker in Lambeth and with a GP practice in Liverpool, Mary returned to

academic life as a researcher with Age Concern and became a lecturer in applied social studies at Liverpool. Her commitment to older people was well and truly established by then. A student there remembers her as 'an inspirational lecturer in social work'.

It was a natural move to want to put that expertise into practice when in 1983 to become Director of Age Concern Scotland.

Since moving to Stirling in 1989, Mary has served tirelessly and effectively on numerous editorial boards, government and voluntary sector organisations, was a member of the Royal Commission on Long Term Care of the Elderly. She is an elected Fellow of the Royal Society of Edinburgh and an Academician of the Academy of the Learned Societies for the Social Sciences. More important perhaps than any of these has been her ability to enthuse and empower students, researchers, architects, designers and builders to recognize the importance of preserving residual function and thereby maintaining personhood to the very end.

And what is Mary going to do now? She isn't saying...having a holiday first, a long think and staying on in her home in Edinburgh. Whatever direction she chooses, we are grateful for her immeasurable contribution she has made to our field and wish her the best and happiest of futures.

MARY MARSHALL: AN APPRECIATION FROM THE UNIVERSITY OF STIRLING

Duncan Sim

The University of Stirling has considerable experience in research and development in dementia and has an international reputation in this field. This experience was initiated by the formation of a specialist Dementia Services Development Centre within the Department of Applied Social Science in 1989, funded jointly by a trust and the University itself. The DSDC at Stirling was the first of what is now a network of Centres, supported by a grant given by the Department of Health. As well as being the first specialist dementia centre in the UK, Stirling's is also the largest and has a high level of policy and practice influence.

None of this could have occurred, however, without the work of the Centre's Director, Professor Mary Marshall. Following the establishment of the Centre in 1989, Mary was appointed, moving from her post as Director of Age Concern Scotland. She had a valuable mix of academic and practical experience, having worked in child care and social work in Lambeth and Liverpool, for Age Concern in both England and Scotland, and as a lecturer at the University of Liverpool. It is this mix which has enabled her so successfully to bridge between academic research and practice advice and to disseminate information to a wide and varied audience.

During her time at Stirling, Mary has provided direction to the Centre and its reputation has grown. Mary herself is extremely well known internationally and she has travelled to and lectured in many countries, but particularly in Australia where she has made many contacts. Her work has become a key reference point for others across the world.

Her international contacts have served the university well and Stirling has hosted a significant number of international conferences and other events, with delegates coming from a wide range of countries. One of the most recent

of these was in April 2005, when Stirling hosted the North Sea Dementia Research Group. Disregarding a biting wind, Mary enthusiastically led us all to the Stirling Castle esplanade to admire the view before treating the delegates to a ceilidh. Prior to the dancing, the Group made a presentation to Mary in recognition of her work across Europe – a very tangible reminder of the esteem in which she is held.

Her particular research interest has been in design and she has a long held concern that the design of accommodation for people with dementia should be as enabling as possible. For many years, she persuaded, cajoled and encouraged the University to support the construction of a building for the DSDC, based on ‘dementia-friendly’ principles. The university provided a site and part of the funding, the remainder being raised by the Dementia Services Development Trust. The resultant Iris Murdoch Building, opened by Dame Judi Dench in 2002, is a lasting memorial to Mary’s work.

The Iris Murdoch Building is designed to help put people with dementia at their ease through the use of visual cues to help individuals locate themselves. There is an extensive use of colour throughout the building to assist navigation. One feature is a ‘memory wall’, which contains alcoves in which familiar objects can be placed to trigger memories. There is also a garden, which is a place of quiet, with focal points to draw people out of and then back into the building. Since its opening, the building has received many hundreds of visitors and Mary rapidly developed a new career as a tour guide, enthusiastically showing people around.

One particularly high profile event which owed much to Mary’s involvement was a project to explore the impact of design on dementia, as part of Glasgow’s programme as UK City of Architecture and Design in 1999. The project led to a number of publications but also to the adaptation of a Glasgow council house for a tenant with dementia, using guidance developed by DSDC. Mary and I visited the house together and were much impressed by the combination of sympathetic design and technological innovations, including alarm systems. Mary spent much of our time in the house rushing

around taking photographs, trying out the technology and inadvertently setting off various alarms. In her enthusiasm, she remained oblivious to the chaos she was causing!

Mary and I collaborated in developing some research ideas on design for people with dementia and, during a visit to the United States in Autumn 2003, I took the opportunity to meet with some American designers and explore the American experience. It became apparent to me very quickly that American thinking was not as advanced as our own and I found myself being referred back to the work of DSDC at Stirling. This served as confirmation that the DSDC under Mary's guidance had indeed achieved a major international standing.

Mary has always stressed the need to disseminate research findings and to promote good practice. This led to a comprehensive dissemination strategy being adopted by DSDC, including the publication of edited books, journal articles, guides for practitioners, carers and people with dementia themselves, and training packs, including a wide range of videos, books and other training materials. Of particular interest has been the promotion of the arts and creativity for people with dementia as a means of helping communication. The production of books and videos to encourage music, dance, activity, creativity, expression and communication by and with people with dementia is an ongoing dissemination activity.

Under Mary's guidance, the University has developed significant teaching in the area of dementia, both at undergraduate and postgraduate level. The MSc programme in Dementia Studies was launched in 1999 and is now offered by mixed mode delivery (mainly online). This has enabled the course to admit students from a distance and there are now a number of European and overseas students on the course. Recruitment for the MSc is made easier by taking advantage of the various international links which Mary and the DSDC have developed.

Outwith the university, Mary has made a considerable contribution to policy debates on the needs of older people and people with dementia and the University's profile has undoubtedly benefited from her activities. One of the most significant contributions which she made was to the Royal Commission on Long Term Care for Older People, chaired by Sir Stewart Sutherland, and which delivered its findings in 1999. One of the Commission's recommendations – rather controversially – was that personal care for older people should be paid for from general taxation. Although rejected by the Westminster Parliament for England, the policy was adopted by the Scottish Parliament, with legislation enacted as the Community Care and Health (Scotland) Act 2002. Mary has always seen the importance of venturing beyond the rarified academic atmosphere of universities and of engaging in policy debates like these and her work, both inside and outside the University, on services to older people was recognised with the award of the OBE in 1997.

Mary Marshall retires from the University of Stirling in August 2005. She leaves behind a Dementia Services Development Centre with a strong international reputation, housed in a state-of-the-art 'dementia-friendly' building. Her contribution to the University has been of major significance and she is a hard act to follow.

THE IRIS MURDOCH CENTRE



MARY MARSHALL AS A COLLEAGUE AT STIRLING

Carole Archibald

It is hard to think of Mary as retired but that is now the reality so here are some thoughts on the experience of working with her at Stirling. I do not want this to be a hagiography because what makes Mary the special person she is her human fallibility. She is modest and is able to acknowledge that sometimes she does not always get it right. She is tough, resourceful with a good sense of humour and she is willing to take risks. This almost sounds like a reference but these are qualities that I think will enable her to seize retirement opportunities with both hands.

She has been such a dynamic and influential person in many areas of dementia care not least in the setting up and creation of the first Dementia Services Development Centre in the world. There will be many accolades coming her way on her retirement but what I want to do here is to share some of my memories of working with Mary for over the past 15 years. It is a form of reminiscence really.

The first is that as an employer she provided a work situation that was unusual in that you were allowed to be imaginative and creative. You were given autonomy and support. You needed to get it right of course but with that caveat it was possible to be at the cutting edge looking at, writing about and facilitating workshops on subjects that few had considered in relation to dementia including sexuality.

Some of the first workshops Mary and I held attracted up to 100 participants and were on complementary therapies. It is now commonplace to think in terms of massage and reflexology in dementia care. Our Trustees had some initial misgivings but the subject has proved to be of continuous interest and of benefit to people with dementia and their carers.

In terms of workshops we did not always get in right for some people. One of the first workshops we held was to teach participants about activities and day care. The day was to be an experiential exercise to help staff to try and imagine what it was like for people with dementia to be in receipt of such care. As many staff consider that what old people need is touch and hugs as they tend to be touch deprived, we started the day by giving each participant a hug when they arrived. Some took to this with gusto that nearly resulted in fractured ribs whilst others were appalled at such contact. We did manage to convey by this exercise that people are all different with needs that vary. Mary and I have laughed about this episode many times over the years and learned from it.

Together and with many others we were involved in the Alzheimer's International Conference held in Edinburgh in 1994. Mary and I had the privilege of working with and directing Laura Sutton, clinical psychologist, and John Killick in a session at the conference that proved to be an outstanding success involving case work and hearing the voice of people with dementia.

People with dementia in acute hospitals, has been an area of work highlighted at the DSDC and we have produced books and videos to help staff address issues in this area of work. In this role I have taken the lead and Mary has worked long and hard obtaining funding and being supportive, and as always, being open to new ways of working.

Mary has of course become a world expert on design and dementia and is constantly in demand at conferences all over the world. I was involved and supported by Mary in writing about specialist dementia units and consultancy work involving new build, plus staff development.

Mary will be sadly missed at the DSDC for her breadth of vision, her generosity of spirit and her resilience and hard work. She will in all senses be a hard act to follow. I wish her well in her retirement and hope that she will have many happy and creative years ahead. She deserves nothing less.

MARY MARSHALL AND THE DSDC NETWORK

Andrew Fairbairn

I am a Consultant Old Age Psychiatrist whose entire career has been based in Newcastle upon Tyne. However, like Mary Marshall, I was born and brought up in Edinburgh.

My first contact with Mary Marshall arose when my consultant psychologist colleague, Elspeth Stirling, invited Mary to hold a seminar in Newcastle on the Stirling Centre. Following the seminar Elspeth successfully bid to the then Northern Regional Health Authority for money for a pilot project to look at the feasibility of running such a centre in the North East of England.

This study confirmed that it should be feasible to create a North Eastern Dementia Development Centre and this subsequently grew into what is now called Dementia North led by Professor Caroline Cantley.

In the mid 1990s, I was a Senior Policy Advisor, seconded to the Department of Health. Again, I used Mary's advice and wisdom to pump-prime a number of other dementia centres across, England, Wales, Northern Ireland and the Republic of Ireland. Without Mary's vision none of this would have been possible.

In her work at Stirling she made service development in the field of dementia academically credible and respectable. She made a particular impact on the training of all disciplines in all sectors of the health and social care economy. Her work on design of care home is internationally renowned.

Finally, on a much more personal note, I remember visiting the Stirling Centre to learn about their activities, which included attending a regular staff meeting. I was profoundly impressed by Mary's inclusive style of leadership as well as her delightful sense of humour. She will be greatly missed in retirement!

WORKING WITH MARY MARSHALL AND THE DSDCs

Tom Dening

‘Whatever you do, look after the DSDCs’, said Andrew Fairbairn, gathering his coat and slipping out of the Department of Health’s office at Wellington House.

I first encountered Mary Marshall giving a talk at an Alzheimer’s conference in Helsinki in 1998, but we didn’t meet properly until later. By then I was working as an adviser to the Department of Health, in the policy branch concerned with older people. I was there at an exciting time, relatively early in the Blair administration and an active period for new policy initiatives. One of my tasks was to represent the Department and to keep abreast of opinion-leading bodies. This included several interesting contacts, such as the Faculty for Old Age Psychiatry in the Royal College, and work with the Audit Commission and the Mental Health Foundation. However, among these encounters, the most stimulating and productive was working with the network of Dementia Services Development Centres.

The Network was already up and running when I came along in 1999. It had a Section 60 grant from the Department of Health to support its meeting costs and also the chairmanship of Peter Fletcher. In those more relaxed times, the English Department of Health seemed willing to support a Network that was not only UK-wide but included representation from Ireland too. So, my civil servant colleague Tim Brown and I pitched up to the converted fruit warehouse in Victoria that houses the Alzheimer’s Society. Towered over by cardboard cutouts of Danny Blanchflower, Ronald Reagan and Rita Hayworth (all people with Alzheimer’s disease), we tuned into discussions about training budgets and the information support to the various DSDCs. Tim and I became more animated when projects for Department of Health grant applications were considered. Part of our role was to encourage the centres to make Section 60 bids and several of these were successful, notably a grant to

establish the centre in the Trent region – the last dot on the map to be filled in.

Within the Network, of course, Mary's was the key presence, as all the other DSDCs were conceived along the same lines of the original in Stirling, aiming to combine the four functions of training, research, information and service development. The other centre directors were all people whom she had personally inspired, and there was an impressive collaborative atmosphere. Centres with better resources were generous to those less fortunate, and projects were often shared between the centres so as to improve the chances of successful applications. In time, the Network ceased to use the Alzheimer's HQ for meetings and rotated them around the individual centres, a further opportunity to see how things were going at a local level.

After the first couple of meetings, it appeared to Tim and myself that we would learn more and understand the Network better if we spent some time with the individual centres. Over a year or so, we visited not only the seven established centres in England but those in Scotland, Wales and Ireland as well. This enabled us to build an individual relationship with each of the directors, extremely useful in terms of understanding local issues and building further local links. Each centre had a rather different relationship with its local statutory providers and academic centres – some being housed by universities and others in NHS or local authority accommodation. As the centres worked closely with the *Journal of Dementia Care*, they were often involved in organising conferences, and this led to several invitations to speak on behalf of the Department of Health. I must confess to enjoying these, especially when the audience asked probing questions about the Government's intentions. At least you know you are really alive when you are being pressed on these matters in public!

Tim and I went to Stirling together. Mary met us at an ungodly hour at Edinburgh Airport and whisked us off to eat a traditional Scottish breakfast. Neither of us could confess that not only had we had breakfast on the plane but also we had been up so early we had eaten something before leaving

home too. We toyed with our sausages and haggis while Mary warmed to her subject. However, we had a terrific day, meeting the whole DSDC team. The view of the nearby hills was the most spectacular outlook of any library I have been in.

The relationship with the DSDC network became so cordial that both Tim and I became caught up in the plans for a collaboration with the Norwegian Dementia Research Institute. We found ourselves on a plane to snowy Oslo for the first so-called North Sea Dementia Meeting and we presented a paper on the development of the National Service Framework for Older People. Professor Knut Engedal and his team arranged a wonderful meeting and the social programme included a visit to the national ski museum. The Queen of Norway visited the hotel during our meeting, although actually to join another group not ours. While in Norway, the opportunity to have longer conversations with Mary arose and it felt to me that, despite some of her reservations about psychiatrists generally, I had been accepted by her. Indeed, to the extent that the Department (me) was invited to form part of a DSDC symposium at the World Congress of Gerontology in Vancouver.

The second North Sea meeting was held in Cambridge, a city that may find itself beside the North Sea if global warming continues. Dawn Brooker and the Oxford Centre were responsible for the academic programme but the social parts fell to me. Tough competition after the Norwegian meeting but evensong in twilight at King's College Chapel went down well. (The third North Sea meeting was in Amsterdam with the cultural highlight being a guided tour of the red light district, another story perhaps.)

However, with the passage of time, the DSDC Network began to feel rather less cohesive. As centres became locally more established, many of their crucial issues were at home rather than at national level. Some key people moved on to other things. Collaborative projects across the Network became more difficult to establish as the academic bodies hosting the individual centres were keen to keep their own grant income. Indeed, at least one centre was absorbed by its local university. Some centres became reluctant

to release their directors for Network meetings and in general it was less clear that quarterly meetings were necessary. By the time I left the Department of Health in 2002, it seemed that the Network would probably wind down, though there would continue to be strong links between some centres for years to come.

By way of postscript - I have since had two further significant contacts with Mary. I was delighted to invite her to join a small group giving presentations on various aspects of dementia care in the UK at a conference hosted by the British Embassy in Berlin. The invited delegates included people from the German health and social insurance systems, and others with relevant interests. We visited an impressive care home in Brandenburg, where Mary was characteristically busy with her camera.

However, our most recent encounter was quite by chance in Orkney during the St Magnus Festival. The twilit night of the summer solstice found us amidst the ancient stones of the Ring of Brodgar, a magical and mystical experience to share with anyone.

YOU KNOW IT MAKES SENSE

Jim Jackson

I first knowingly met someone with dementia when I was an unqualified nursing auxiliary in a large psychiatric hospital during a summer vacation nearly 40 years ago. It was like entering another world hidden from the suburbia in which I grew up.

The primitive attitudes many staff held about patients were mirrored by the ignorance of much of the general public. Thankfully, since then there have been immense improvements, although by no means enough, in all mental health services including dementia care. Much of the latter has been due to the growth of the dementia movement and the establishment of 'dementia services development centres'.

Mary Marshall has been the director of the Dementia Services Development Centre at the University of Stirling since its inception in 1989, the first in Scotland and the rest of the UK. As the chief executive of Alzheimer Scotland it has been a privilege to work with Mary and her colleagues at Stirling in jointly raising the profile of dementia and spreading the message that there are solutions, positive steps, which can be taken in response to this illness. Mary has been an inspiring leader in promoting good dementia care, high quality services and effective training for the staff that make it happen. She has helped put dementia on the world map. In doing so she has played a major part in making health and local authorities, plus the voluntary and private sectors, begin to accept their responsibilities for the growing number of people with dementia in our communities.

Mary's contribution to improving our understanding of good dementia care has been remarkable for its range as well as the clarity with which it has been communicated. Not content with helping practitioners improve their skills in running care homes, day centres or home care services, Mary has gone on to look at the design of all premises used by people with dementia culminating in

the Iris Murdoch Centre to house the University of Stirling Dementia Services Development Centre which is a fascinating demonstration of dementia friendly design principles.

A major theme of Mary's for the last decade or more has been the importance of improving our ability to communicate with and understand people with dementia. The seminal *Hearing the Voices of People with Dementia: Opportunities and Obstacles* by Malcolm Goldsmith (1996) was written with her active support. John Killick became the poet-in-residence of the Dementia Services Development Centre and helped open our ears to what people with dementia could say. Kate Allan produced a beautiful practice manual *Finding your Way: Explorations in Communication* (2002) which showed how we can all improve the way we communicate with people with dementia. All this demonstrates another of her assets which has been her ability to attract creative colleagues who will roll back the boundaries of our understanding.

Not surprisingly Mary has been in demand to serve on many committees. As a member of the Royal Commission on the Long Term Care of Older People she was a powerful voice for the introduction of free personal care so that for people with dementia *inter alia* there could be greater parity with other illnesses. Sadly this has not happened in England, Wales and Northern Ireland. However, in her home territory of Scotland the Scottish Executive has been much more receptive to the idea and accepted the recommendation of the Care Development Group, of which Mary was a member, to introduce free personal care. Mary also chaired the working groups which drafted the National Care Standards (for Scotland) for care homes for older people and support services in Scotland. She demonstrated a special ability to weave together the voices of the sometimes competing professional interests and the users of these services.

Mary has not been afraid to venture into what initially seemed unsuitable territory. To some, technology and dementia may generate science-fiction images that could hardly be said to be 'dementia-friendly'. Instead, the

picture which emerges emphasises the ability of technology to help sustain the person with dementia's independence and minimise the effects of their disability – lights that gently come on automatically when you get out of bed in the middle of the night, thermostats that prevent you scalding yourself, electronic devices which remind you about particular tasks and much more. Taken in conjunction with the principles of good dementia design, technology can do much to sustain living at home for people with dementia.

A final example of Mary's many interests is the importance of eating well for people with dementia. She could have written a book about diet and good practice in feeding. She did not; instead she edited and wrote sections of the celebratory *Food, Glorious Food, Perspectives on Food and Dementia* (2003) which again demonstrates a zest for making good dementia care enjoyable and maintaining a 'jargon free style' of writing.

I hope by these few examples I have been able to demonstrate Mary's ability to reach out to all she has worked with – government ministers, doctors, people with dementia, social workers, care workers and family carers. She has had no need to use over-complicated theories or models. She has just had a unique way of making good dementia care straightforward – the right thing to do. You know it makes sense.

MARY MARSHALL: GROUNDBREAKER

John Killick

The first I heard of Mary Marshall was when she rang me up in 1993 to say, “I hear you are doing interesting things. Come up and see us.” At that time I had been working as Westminster Health Care’s Writer in Residence for a couple of years, only one of which had concentrated on people with dementia. A short article about me had appeared in the *Journal of Dementia Care*.

I accepted the invite to Stirling and duly rolled up expecting a chat with Mary and a tour of the Department. “Hurry up” she said, and took me along to the room which in those days functioned as a library. When she opened the door I was confronted by a table round which the staff were gathered. On it were food and drink. “Grab a plate and a glass. The seminar begins in five minutes” Mary said. “Who’s giving it?” I asked. “You are” she replied.

Afterwards she took me to her office. She seemed pleased with how it had gone. “I’d like you to join us as Writer in Residence” she said, “but at present I have no money to pay you, so I propose to make you an honorary member of staff. We’ll pay you as soon as we can afford to.” She was as good as her word. Very soon DSDC had published my pamphlet *Please Give Me Back My Personality*, we had made the video teaching tool *One-to-One*, and I was running training courses, as well as participating in staff meetings.

The first presentation I made at Mary’s request was as part of the groundbreaking *Experience of Dementia* session held as part of the 1994 Alzheimer’s Disease International Conference in Edinburgh. I read poems made from the words of people with dementia, and assisted the psychologist Laura Sutton in presenting an account of a therapeutic session. Tom Kitwood did one of his celebrated role-plays. The only discordant note was struck by a less than person-centred American psychologist; we winced every time she pronounced the term “The Alzheimer”!

Generally speaking, it was an occasion which made a deep impression on many who attended, and those who took part.

Communication was a theme which Mary made very much her own. She had already identified it as essential to good care, and Malcolm Goldsmith was already working on his seminal text *Hearing the Voice of People With Dementia*. When Kate Allan was appointed to follow on from his lead, she and I decided to write our own book and Mary found us some money to buy us time to write; this became the Open University *Communication and the Care of People With Dementia*.

In 1999 Mary said to me, "It's about time you had your own development project. What would you like to do?" I said, "Cover all the arts not just writing." She went out and found the money for the project, the first of its kind, I think, anywhere in the world. When in 2002 the new Iris Murdoch Building was opened we at last had a gallery where the works produced by people with dementia could be properly displayed.

In 2003, whilst I was working in the States for a week, the University suddenly twigged that I had reached retirement age two years previously, and peremptorily terminated my contract. Mary immediately made me a consultant, and the work proceeded seamlessly.

Mary has been a tireless networker, an essential characteristic if you want to influence the movers and shakers of this world. Very early in my relationship with Stirling Mary and I gave a joint presentation at the Annual Conference of Social Work Directors in Scotland. At the end of the day there was a cocktail party. I knew no-one, but she introduced me to somebody she hoped I'd find congenial and set off to do the rounds. We came face to face again towards the end of the function. "Just a minute" she said, "that man over there is the only person I haven't spoken to" and she set off in pursuit of him.

In terms of developmental decisions I believe Mary has shown unfailing flair and commitment. She has never let protocol and petty rules stand in her way.

This has not always endeared her to the authorities. I believe that their intransigence may have aggravated her sorely. But the maintenance of her style of operation has meant that she has been able to stay one step ahead of the rest of the field in identifying issues and pursuing policies. (It is no accident that every staff meeting would begin with her asking the question “What are the hot topics this month?”). She is a genuine groundbreaker, determined, thorough, and a thoroughly nice person at all times.

PROFESSOR MARY MARSHALL OBE: A TRIBUTE

Jane Gilliard

When Mary Marshall retires in August as Director of the Dementia Services Development Centre at the University of Stirling, a chapter will close for the Centre, the University and the world of dementia care. Mary has led the Centre since it was first established in 1989, and her name has become synonymous with the innovation, flair, creativity and professionalism for which the Centre is world renowned.

Many will know of Mary's work at Stirling – few will know about her earlier career. Having studied at Edinburgh and London, Mary first became a Child Care Officer in the London Borough of Lambeth. London is a place that Mary enjoys visiting, but not one where she was happy to live, so after 2 years she moved to Liverpool where she stayed for the next 13 years. She worked first as a social worker attached to a GP surgery, then organised a research project for Age Concern Liverpool about discharging elderly people from hospital. She next became a lecturer in Applied Social Studies at Liverpool University, and for a year was the Director of the Diploma in Social Studies course. Her ability to inspire others was already clear – I was recently in her company when a former student told Mary how much she had valued her teaching. In 1983 Mary returned to her home country and took up post as the Director of Age Concern Scotland, a post which she held until 1989 when she moved to Stirling.

In taking up the position at the Dementia Services Development Centre in Stirling, Mary was able to combine her social work and academic pasts with her personal experiences of having cared for her father who had dementia. This combination has led to her passion to ensure that people with dementia receive the best possible care and that everything possible is done to enhance their rights and independence. Her creativity means that Stirling is always one step ahead of the game, whether that's researching the enabling effects of the built and social environments, technology, the use of the arts as a medium to engage with people with dementia, or considering the next group

whose needs have been overlooked – people with learning disabilities, or people with alcohol related dementia.

When she wasn't at work at the Centre, her contribution was valued in so many other ways. She was, for example, a governor of the Centre for Policy on Ageing; a member of the Royal Commission on Long Term Care of the Elderly; she is an Academician of the Academy of Learned Societies for the Social Sciences; a Fellow of the Royal Society of Edinburgh; a member of the Edinvar Housing Association Board and a member of several journal advisory boards.

I first met Mary in 1990 when I was a new recruit to the world of dementia care. I already knew her name and her eminence, and she recognised in me (as she did in so many others) a fresh but very enthusiastic convert to this unglamorous and uncared-for world. She was warm and gracious in supporting my work and helping me in my career. In 1994, when I had an opportunity to spend more time visiting the Centre, she encouraged me to set out on the road that led to the establishing of Dementia Voice, the south west's dementia services development centre.

So, what are my personal memories of working with Mary? She is the most generous host. It was as if she had bought herself a flat in the centre of Edinburgh just so that she could share it with visitors. In fact, there were occasions when I was working in Edinburgh or Stirling and Mary invited me to stay at her flat, but I never once saw her while I was there. She might be coming and going at different times, or she might even be abroad. More often than not, there were other visitors who were also passing through and sampling her wonderful hospitality.

Mary and I were lucky to be able to travel together at various times to international events. I remember a magnificent ferry ride with her from Vancouver out to Victoria on Vancouver Island to see their use of technology in action. The home we visited had a bird table and Mary checked to see if it had any food on it. This was her yardstick for measuring the quality of the

care being provided in the home – if they could look after the birds, the care for the staff and the residents was probably alright too!

Perhaps the most bizarre experience we shared was in a forest near Helsinki. Taken there by three Finnish colleagues, we spent the morning looking for mushrooms. Our hosts cleaned and cooked them for us making the most magnificent dish, while Mary and I (together with another colleague) divided our time between the searing heat of a Finnish sauna and the icy cold of the lake outside! We slept extraordinarily well that afternoon!

There are many of us who are so much richer for having known and worked with Mary. Countless people with dementia all over the world are now in better and more dignified care environments, receiving a higher quality of care, with a greater variety of activities, and superior engagement with them as people – all because of her influence. It is impossible to estimate the numbers of professional staff whose lives and careers have been enriched because of the impact of her work. I count myself very fortunate to be included amongst them.

But Mary would want us all to know and understand that her retirement is only the end of one chapter ... the book will go on. She started the work at Stirling and she is fervent in her desire to see it continue. And what a fabulous foundation she has laid!

MARY MARSHALL: FRIEND TO PEOPLE WITH DEMENTIA

Pat Smith and David Jolley

We worked together in Geriatric Medicine and Psychogeriatric Medicine services in South Manchester in the 1970s and 1980s. It was through this that we were fortunate to meet Mary, one of the many wonderful people we have known who have given their lives to improve the care of older people especially those who develop dementia. It was not a fashionable thing to be doing, but there was a strong feeling of friendship amongst the pioneers in all fields. It was Pat's reputation as an experienced practitioner and teacher of Social Work which established the link, which has stayed secure over more than a quarter of a century. Looking back, Pat reflects:

The trouble is I admire and respect Mary greatly and the task of writing about her seems very daunting. I first met Mary when she was a lecturer at Liverpool University and I was based at Withington Hospital. Mary needed more work placements for her Social Work students and I, courtesy of DJ [David Jolley] and Professor John Brocklehurst and the rest of the multi-disciplinary teams, did my best to supply these. Social Work with elderly people was not seen to be exciting or interesting- let alone worthwhile, by the students of the different courses. They often came on placements with some reluctance despite their tutor's encouragement. What made Mary outstanding for me was that she was clearly interested in the challenge presented by older people and their illnesses. She encouraged her students to think widely about old age and all that went with it. Occasionally Mary would ask me to go to Liverpool and talk with a group of her students. I always found them lively, questioning and not afraid to be a little argumentative. I much admired the way that Mary must have enabled those different groups to come together and be forthcoming. Mary's interest in older people and her imaginative ideas for maintaining their dignity just seemed to grow.

Recently I have been reading some guidelines for dealing with vulnerable adults. It has reminded me of sitting in a café in Liverpool listening to Mary holding forth about the rights of the individual and the need to support them

whenever there was talk of using Section 47 of the National Assistance Act 1948. Mary went on to 'greater things' when she left Liverpool and yet despite her busy life she always kept in touch. Her books have been of great use to so many people and I have given them as presents to aspiring Social Workers. My final thought is of the story Mary told me when she had not long been in Scotland. She must have been conducting a survey of older people to see who they found the most helpful in an emergency. The police were favourites with Social Workers a long way down, 'because they make too much fuss'.

For DJ and the rest of the team of nurses, paramedics, doctors and students, it was wonderful to have Pat and her Social Work colleagues join generously with us and show us how to make things work in the complicated world of eldercare. Additionally wonderful that they shared in our teaching and brought with them students who would take forward better services and greater expectations for old people (including those with dementia) to towns and counties around the North West. I met Mary for the first time on the corridor of Healey House, our multi-purpose Psychogeriatric Unit. She was clearly pleased and excited to be there where the action was. To meet the nurses, see the patients and their families and to sit and talk a while in the small quiet room in which we held our clinical and teaching meetings. Not for her the detachment of a distant Ivory Tower. She listened and saw things quickly, a natural and intuitive observer, gathering ideas and setting them in context with other practices she was aware of from her travels. It has been this skill and devotion which she has harnessed and honed during her years at Stirling. The visionary initiative which gave rise to the Stirling DSDC from the ruminations of Scottish Action on Dementia, Alzheimer's Scotland and the Scottish Office, could not have dared to expect anyone so perfectly capable of capturing those dreams and making them into real-time action. In addition, as we know, Mary has dreamed her own dreams and taken the initiative further. She has given others confidence to share their practices, has generated training and educational programmes which have been copied by others, she has masterminded evaluations and underpinned a growing evidence-base. People have flocked from around this country and from

around the world, to look at what she has been doing, she has welcomed them, encouraged them and supported their embryonic efforts to carry the ideas to people in other places. Her spirit of honesty and generosity has endeared her to generations who follow her, follow in time and in like-style.

The debt that is owed to her is one which ranges across all the professions. By turns she gave time, expertise and creativity to older people and to those with dementia. Through them, the lives and values of patients and families have been enriched and sustained. There is now dignity, pride, even mirth, where there was despair and isolation.

There is little doubt that Mary will continue to contribute to the work in her 'retirement'. We shall all be pleased to receive more of her wisdom, but it is right to be saying 'thank you' for what she has already given.

KNOWING AND DOING

John Grimley Evans

Medicine can make hard demands of those who come to it under the compulsion of a vocation rather than the option of a career. Not least is the competition for time, energy and intellect from the laboratory and from the clinic. The science is fascinating enough to fill an entire life; there is a numinous beauty in knowledge structured by the great transcendences, whether of relativity or Darwinism. But the vocational itch of medicine can be salved only by doing, not just knowing.

Thirty or more years ago Mary Marshall was a researcher in a department of social medicine and I was a larval chronic disease epidemiologist. A few years later she was directing a dementia centre and I was a newly hatched geriatrician. We could hardly have ventured into areas of medicine more messy intellectually, or more challenging in practicalities. Indeed, many authorities questioned whether the global impairments of old age and dementia were matters for medicine and doctors at all. The medical establishment saw ageing as the inevitable ticking of a genetic biological clock. Early-onset dementia was presumed a disease but senile dementia was “normal ageing”, and normal ageing, by definition, could not be treated; indeed there would be something almost impious in trying to do so. Social scientists protested against “medicalisation” of senescence. Old age they claimed was a social construct, and its infirmities of only secondary significance. One social sciences graduate gained a doctorate in asserting that senile dementia was not a disease but a rational psychological reaction of the poor and oppressed against the injustices of capitalism.

Medical responses to human senescence were dominant in Britain because political interest in old age focused on operational difficulties in the National Health Service. Old people, and especially demented old people, had accumulated in large numbers in hospital beds, compromising both acute and

elective services. The problem, created by doctors, could only be solved by doctors, but like Oberon's spirits, of another sort.

For geriatricians the first phase was easy enough given enthusiasm and the goodwill of colleagues in the medical and social services. Among the long-stay patients in hospital sufficient ameliorable illness and disability had been overlooked for some people to be helped home again and so provide elbow-room for reducing bed numbers and improving staff/patient ratios. The more fundamental problem was the lack of adequate knowledge and a research base for the design and delivery of rational services for older and demented people. Significant scientific progress in dementia research began after Bernard Tomlinson and his Newcastle colleagues showed that the pathological changes of senile dementia were identical to those of Alzheimer's disease. The key re-labelling of a "normal" age change as a "disease" opened up the flow of research funding. But at a practical level much had to be done without waiting for the results of research.

Politicians and bureaucrats would have us believe that if there is no evidence on how to deal with a patient's problems it is proper and cheaper to do nothing. But doing nothing is not an option for a doctor or a nurse faced with the immediacy of human need. In medicine, knowledge is the servant of compassion, and, where knowledge is lacking compassion must provide the rationale as well as the motivation for action. Compassion - "feeling with" - is easy enough with people of our own age, sex, nationality, and social class. Wider understanding of how people feel about their lives and illnesses is more elusive. Lectures on "communication skills" can teach us how to bluff, to say the politically correct things, and to disguise inattention and boredom. But to understand why an old lady will not take her tablets or an old man shouts all night requires emulation, effort and experience - emulation of our best teachers in modes of enquiry, effort to collect all relevant information, and experience to synthesise a list of most probable explanations. Dementia, however, defies true understanding. Most of us have at some time been physically ill; we know pain, nausea, even the apparent imminence of death. Many of us have experienced mental illness, and know what it is to wake one

morning and to be another person in a strange world. But the old order returns sooner or later; we are back where we came from and, perhaps, know the place better. There is nothing we can draw on from our own lives to simulate the experience of unrelenting dementia, nor, after the early stages, can the sufferers themselves tell us. They live, or partly live, in an apparently autochthonous Present that fades, leaving no trace, into another Present. The Past, the reminder of who they have been, twists and fades like a dream. For their sakes and ours we need to construct, in what Tom Kitwood called poetic fiction, some intuitive picture of the dementia experience that preserves the central image of a sentient and worthy fellow-being.

While we cannot know what dementia feels like, the distress of families and the strain on professional carers are only too accessible to understanding. Families who can cope no longer purge their guilt in attacks on the professionals who have to take over. Nurses and doctors have to learn to recognise and control the resentment at this injustice lest it rebound on the hapless patient. Marjory Warren, the “Mother of Geriatric Medicine” was among the first to appreciate that the morale and self-respect of carers was crucial to the wellbeing of elderly and dependent people. Gaining recognition for this significant truth in British health services has always been a struggle, a struggle grown much harder since administrators became managers, and patients’ relatives became consumers. You should not have to be a saint to care for old and demented people, you should not have to invest so much of yourself in your work that you burn out with half your professional years still before you. Spouses and other informal carers should not be destroyed by burdens laid on them by cost-effectiveness calculations.

Much was achieved in the last decades of the 20th century. Things are so much better now that it is easy to forget what we owe to people like Tom Kitwood and Mary Marshall for defining standards in the content and delivery of care for people with dementia. In my student days I saw demented and terrified old gentlemen held onto hospital beds with pig nets. Physical restraints are still too much in use but more rarely and more surreptitiously than in the days of universal cot-sides and apron strings tied behind chair

backs. Even pharmacological restraints are falling in respectability if not enough in usage. But we would look largely in vain for an evidence-base that would provide rigorous scientific justification for one-to-one nursing rather than physical or chemical restraint in responding to the challenging behaviour of demented people. We do it because it is the decent and courteous thing to do, and in preserving their human dignity we preserve our own.