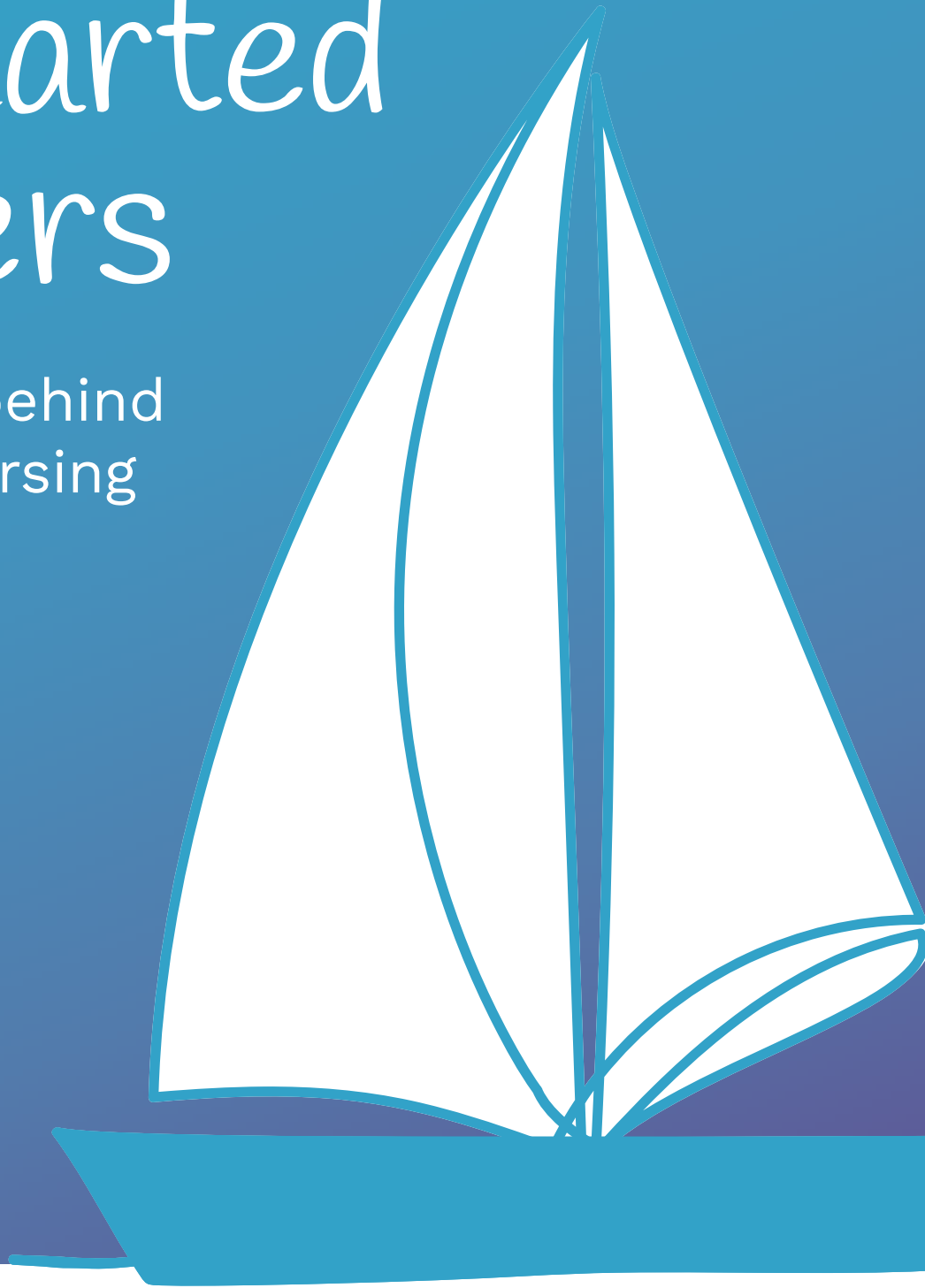


Sailing into uncharted waters

The story behind
Admiral Nursing



Jane Jason



Sailing into uncharted waters

The story behind
Admiral Nursing



For all families living with dementia
and the many Admiral Nurses who offer
their compassionate, expert support to
help them face the challenge

In memory of Admiral Joe who made it
all possible

"We were sailing in uncharted waters in the early 90s, and it is heartening to see the enormous role that has been played by the Charity and the Admiral Nurses in raising awareness about dementia and the need for support for carers"

Hilary Leslie



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Foreword

The need had been obvious for some considerable time, but, like so many things that linger unacknowledged under our very noses, it was assumed someone else might tackle the problem. Well, there was no 'someone else' – that is until Jane and her family came along.

The idea was simple but brilliant: why not create specialists who could assist families affected by dementia the same way Macmillan nurses help those with cancer, offering a life raft of support and guidance to ease the pressure of caring.

So Jane's request for me to become one of the first patrons of the Dementia Relief Trust (as it was then called) was irresistible, and over the next few years I was privileged to see at first-hand what a difference Admiral Nurses made to the lives of so many families.

On other occasions I was profoundly moved when reading the citations at the Charity's annual award ceremonies. Chatting to these special people made me feel incredibly humble – simply because their chosen careers were infused with the overwhelming desire to help others. They were winners in more ways than one.

Several years later came that unexpected time when my own family needed an Admiral Nurse. My wife Liz had been diagnosed with Huntington's Disease, and there came a point where looking after her sucked our entire family into a deepening well of depression – especially my magnificent daughter Kate, who put her chosen career on hold to look after her mother at home. That is when Alison arrived to relieve the pressure – not just an Admiral Nurse, but admirable in every possible way. Her regular sessions played a key role in delaying by almost two years my wife's inevitable move to a nursing home as her condition deteriorated.

So I have experienced at first hand the warmth, the skills and gentle help of Admiral Nurses, as well as being involved near the very beginning of the brilliant concept that was to grow into such an outstanding service to society. Their work is life-changing, not just for those they help, but for anyone privileged to see them in action.



With Admiral Nurse Alison

The journey from the early days when they didn't know where the next few pounds of funding would come from has been an impressive one. More than a quarter century of hard work and dedication has created what is today a £19.4 million charity, Dementia UK, extending into different parts of the UK – and with the potential to reach many more.

Jane's book charts the ups and downs of a journey to develop the kind of help which extends to the very heart of one of the great issues in our society – care in one's own home, which successive governments have wrestled with. It is a template in determination, and I commend it to every person and family starting or already embarked on a dementia journey of their own.

It is also an invaluable guide to the future, as it shows the real potential for expanding still further the work of Admiral Nurses, and will hopefully be an important catalyst in achieving that.

Sir Martyn Lewis CBE

Patron 1997, Dementia Relief Trust
(now Dementia UK).

Introduction

Many consider themselves lucky to belong to a happy and close family. I therefore feel that I have been incredibly fortunate to be a member of two such institutions, one by virtue of birth and marriage, the other purposefully created. I have felt for some time that recording the history of the Charity was a project I would dearly love to complete while I was still able.

The original idea was to produce an accurate account of the background to setting up the Charity which is now Dementia UK where none previously existed, as well as to maintain a record for the archives of my father's foundation, originally the Joseph Levy Charitable Foundation. The Foundation has over many years invested heavily in the creation of this national charity. I am grateful to both organisations for their support of this project.

It was never intended to be a fully comprehensive historical record; the aim was to select and accurately report the key milestones leading to the development of Admiral Nursing and the Charity's growth. The story spans from the late 1980s to 2015 when I retired from the Board, focussing primarily on the early, most challenging years.

As with any innovative idea, during the three years of the original Admiral Nurse project we encountered opposition, and valuable time was spent justifying the focus to support the family carer. I have endeavoured to describe the challenges we faced as we struggled to gain a foothold in an increasingly competitive charity world. We relied heavily on the kindness and loyalty of family, friends and colleagues, and the very much valued support of our celebrity Patrons and Ambassadors.

I would like to add my gratitude to my husband for his tolerance of the many disruptions over the past four years, including unscheduled audio and video calls at all hours when deadlines were faced. I acknowledge here my appreciation for the support shown by my family over the past thirty years.

At the start of this endeavour in 2019, I formed a working group without whose backing none of this would have been possible. I am immensely grateful to them all for their patience, loyalty, and the ability to maintain a sense of humour throughout the extended process. I owe a debt of gratitude to the following people who have patiently supported me over the four years it has taken to write this story.





Hilary Leslie, who had joined me early in 1994 at the beginning of this uncharted journey when she agreed to assist me in formally establishing the Charity, remaining to produce the Charity's first fundraising programme. Hilary's immaculate attention to detail ensured that events over those first few years have been recorded for posterity.

Barbara Stephens, the Charity's second Chief Executive, whose accurate recall of events far surpassed my own. Working together again has resurrected memories of the Charity's formative years. I thank Barbara for the time she has dedicated to this publication and the narrative she has contributed to describe some important milestones and key developments in Admiral Nursing throughout her fourteen years in office.

Annelene Tearle, with whom I had also worked previously, joined us as my research assistant and archivist, juggling several roles in support of the project. Her flexible work ethic matched my own and we forged a successful and relaxed partnership. She also makes an excellent cup of tea! **Liz Anderson**, joined us some time later when quite by chance I discovered she had recently retired from a long and successful career as Arts Editor at the Spectator and was willing to come 'on board' to assist with the design, proofing and editing stages. Finally, without **James Fitzpatrick**, former Director of the Joseph Levy Foundation, working voluntarily, acting as Project Manager, I doubt if this project would have ever got off the ground. James has quietly and efficiently continued to service the project whilst keeping us focussed on the task ahead. He has worked all hours to ensure our targets and deadlines were achieved.

Since we began in July 2019, Annelene and I have read and archived many completed questionnaires and conducted over fifty face-to-face interviews. Early on we were forced into a new way of working, learning to rely on video communication such as Zoom or Teams to record individual memories. In many ways the imposed isolation periods during 2020 and 2021 due to the Covid Pandemic worked in our favour; everyone was readily available and more



than willing to speak for so long that transcripts could cover as many as twenty pages!

I finally made the decision to replace my trusted, yet aged laptop which operated at the same speed as its septuagenarian operator. Born prior to this ever-changing computer age I will never totally master modern technology; relying more often than not on a simple Post It note as an aide-memoire!

I must pay homage here to the IT guru **Sylvester Okungbowa** who saved my life on more than one occasion. The worst was when I genuinely thought everything was lost. I could not find the draft and received the message "this document cannot be found." Almost hysterical, I located Sylvester travelling along the A406 towards Brent Cross shopping centre. Without hesitation he pulled into the IKEA carpark and miraculously found and reinstated everything remotely from his phone – pure genius!

Nothing just happens, and I was eager to illustrate how the pieces of the jigsaw slowly began to fit together to create the Charity and the unique 'Admiral Nurse family'. I have seen valued working relationships develop into lifelong friendships that miraculously survived the early pressures and uncertainties. Included are memories gathered from original Admiral Nurses and other members of the early Dementia Relief Trust/**for dementia** charity, though I acknowledge that for every professional I mention there are many more throughout the country working to extend the vision of Admiral Nursing.

Over the years Admiral Nurses have contributed in their own way to improve the lives of those affected by dementia. I am humbled when they thank me for creating the job they love, explaining how privileged they feel to be able to support these families. As understanding has improved it is now openly acknowledged dementia affects everyone. The effect it had on members of my own family prompted us into action so that we, in turn, were able to make a difference.

Key Charity Milestones



1990

- Admiral Nurse (AN) Project 1990-1993
- First Admiral Nurse appointed

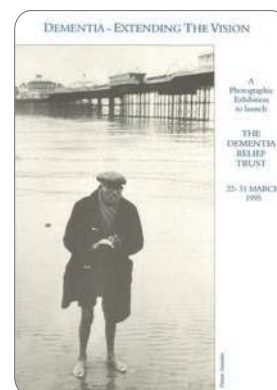


1993

- Funding for AN Project extended 1 year

1994

- Charity registered as The Dementia Relief Trust
- Charity office established in Waterloo Place W1
- Hilary Leslie appointed Fundraising Co-ordinator/ Director of Fundraising and Communications
- First AN Teams established (Camden & Islington, N.E Westminster & Riverside)



2007

- Jane Jason awarded OBE
- Launch of Admiral Nursing DIRECT Helpline

2005

- Charity's 10th Anniversary
- Uniting Carers Network Launch event
- 10th Anniversary Carol Concert
- Jane retires as Chair
- Victoria Wilson appointed Chair

2003

- Charity rebrands as **for dementia**
- Admiral Nurse 'Competency Framework' launched



2008

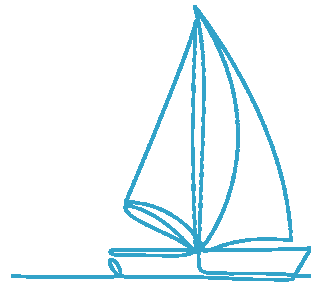
- Cllr. Louise Hyams' Mayoralty 2008-2009



2009

- First Tea Party – 'A Tea Party to Remember'
- Ann Windiate appointed Chair





1995

- Official Charity Launch Event
- Charity office moves to Sackville Street W1
- Huw Meredith appointed Development Director/CEO

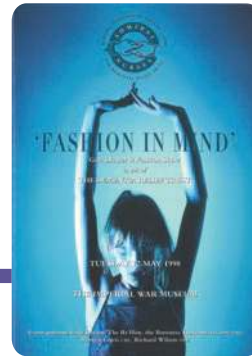
1996

- Parkside AN Team established
- First Admiral Nurse Service Launch – Parkside



1998

- 'Fashion in Mind' first fundraising event
- The October Club Dinner



1999

- Charity moves to Camden NW1
- Barbara Stephens appointed CEO



2001

- 2001-2004 'After Dementia' Millennium Awards



2000

- Training Programme joins the Charity
- Cllr. Michael Brahams' Mayoralty 2000-2001
- First annual Carol Concert



2010

- Charity announces new name – Dementia UK
- 'Time for a Cuppa' annual event launched

2012

- Ann Windiate retires as Chair
- Rosemary Clarke becomes Interim Chair



2013

- David Croisdale-Appleby appointed Chair
- DUK refocuses Charity's work on Admiral Nursing
- Hilda Hayo appointed Chief Admiral Nurse/CEO
- Charity moves to the Resource Centre N7

2015

- Charity celebrates 25 years of Admiral Nursing
- Dementia UK rebrand
- Jane retires from the Board
- Jane becomes Honorary President

Dementia – setting the scene

In the 1970s and 80s any form of mental illness was readily dismissed, and patients, including those with dementia, were incarcerated in the large psychiatric hospitals which abounded at the time. The anxiety surrounding dementia was due to the social stigma related to the condition, caused predominantly by a lack of knowledge or understanding. There was little or no support for the few who were able to be cared for at home. As these large institutions closed, no suitable alternative was identified for those who had been detained for so long. They were totally unable to live safely and comfortably in the outside world.

There have certainly been terrible stories of the conditions in the mental hospitals, which housed massive wards of up to forty patients run by limited numbers of staff. Mark Lawton, the very first Admiral Nurse, told me: *“I remember my first day on a ward – a huge 34-bed ward. I nearly turned on my heel but I stuck at it. I’ve never looked back really.”*

Dementia care was confined to general nursing, with no specific training and no dedicated specialist dementia nurses or carers. Dementia patients would be found languishing in geriatric wards in general hospitals, since, when cared for at home, their families constantly struggled without information or adequate support. I learnt though that many witnessed the gentleness and kindness of staff to patients who had often been forgotten by their families. Peter Carter (previously Chief Executive of the Royal College of Nursing) recalled: *“Most people with dementia ended up in the old mental hospitals. I think people were written off, there was a sense of what could you do? You’d have wards of 40/45 people with 2/3 staff; they were overcrowded; they were underfunded, but I saw a lot of kindness.”* Sadly, today hospital beds are still being occupied by elderly patients who could be cared for at home if there was adequate support for these families in the community.

“A sweep it under the carpet illness”

Dr Stuart Sanders

Although there have been real advances in care generally there are still many gaps. Those with dementia still remain the least likely to attract attention. Regardless of the unenviable reputation of dementia being at the so-called ‘bottom of the pile’, several nurses including Hilda Hayo, currently Dementia UK’s Chief Executive and Chief Admiral Nurse, found their time on these wards so rewarding they moved to specialise in dementia care. Hilda commented about her time spent on one such ward: *“You don’t just see people as conditions, you see people as a whole. I have always from that moment wanted to make a difference to people living with dementia.”*

The modernisation of the nursing profession began during the 1980s, when formal nursing apparel was updated. Starched dresses were abandoned in favour of trousers, and the traditional cap and cloak disappeared. Medical scrubs, predominantly in soft blue for nurses, became a more common component of a nurse’s uniform. This sterilised outfit offered minimal risk of cross infection and increased comfort for working. Scrubs were to become more commonplace as the number of men joining the nursing profession increased.

“There was a complete refusal in society to acknowledge any kind of mental disorder, even in old age, almost as if it was seen as a kind of moral weakness, rather than an unwanted but inevitable, in some cases, illness”

Joanna Trollope



Admiral Nurses do not wear uniforms unless situated in a hospital or other formal setting. However, some of the longest serving Admiral Nurses are pictured here in uniform during their nursing training.

Admiral Nurses now wear an identifying lanyard or badge when working.



Until the end of the 1980s discrimination against people with dementia remained. Family carers continued to be met with little or no possibility of any practical help. GPs were often found to be amongst the most unhelpful. Most people with dementia were dismissed and expected to manage as best they could. Medication did not exist to treat any form of dementia. Today, with increased information and qualified support available for families, the focus is moving towards helping them manage their lives appropriately.

Dementia had always been considered a condition of the elderly – even in the early nineties, it was still being referred to as ‘senile dementia’. Although more prevalent amongst elderly people, it is no longer automatically considered a natural progression of old age.

Beginning the journey

When my father became ill in the early 80s my parents were living in Westminster. In spite of having close access to the best medical care my mother came up against various obstacles when seeking a diagnosis for my father. Their trusted long-time GP had recently died and his immediate replacement proved extremely unhelpful. My mother had been very upset at the lack of sensitivity shown when told bluntly that nothing could be done to help my father.

I was absolutely furious and recommended my own GP, Stuart Sanders, who was also a personal friend. I had made this suggestion some time previously but my mother had originally preferred someone a little older. My parents subsequently

became patients and Stuart treated them both with great patience and kindness. He and his wife Kathryn have also been long-term active supporters of the Charity. My father was referred to Consultant Psychiatrist Dr Monica Greenwood and soon became one of her patients.

A little later, when accompanying my mother to a support group recommended by Monica, we met the renowned pioneer Margaret Butterworth. Margaret seemed to be involved in every dementia activity in the borough and beyond. It appeared Monica and Margaret were already working closely together. Meeting them proved to have a great influence on the way my life developed.

Dr Monica Greenwood

Dr Monica Greenwood was a Consultant Psychiatrist at the Middlesex Hospital, with a special interest in the elderly. She was appointed in 1979 to develop an old age service for central London. Having been introduced to Monica in her professional capacity I then sometimes met her at the support group for carers I attended a few times with my mother set up by a lady named Margaret Butterworth. Her determination helped achieve much where others would clearly have failed. Though Monica's resolve to improve dementia care was once described as wanting to kick down doors when it would have been simpler to turn the handle, she showed a gentle, kind and compassionate side to her patients. Her interest in the provision of good quality training for those working with the elderly helped improve the care provided and enhanced careers. Monica played a major role in placing Admiral Nurses on the map and remains a loyal friend of the Charity, now called Dementia UK, of which she was a founder Trustee.



Margaret Butterworth

The late Margaret Butterworth was a remarkable woman, graduating from Oxford at a time when few women even attended university. She possessed very persuasive powers, endlessly fighting for what she believed in. Margaret was a glorious mixture of confidante, lecturer and mentor rolled into one. There were times throughout this journey I could still feel her looking over my shoulder. Margaret's boundless energy left no stone unturned; her personal family experience caring for her father led her to devote the rest of her life to improving the lives of others affected by dementia – she was a true pioneer. Margaret brought together a number of family carers to form the active carers' group CRAC Dementia. As a founder trustee of the Dementia Relief Trust (now Dementia UK), Margaret helped to lay the solid foundations on which the Charity was built, before leaving to join another charity to improve the quality of activities for older people.



Creating change – the voice of family carers



The image of dementia has changed over the last three decades. In the 1980s and early 90s people with dementia were 'unseen'. We used to speak about people 'suffering' from dementia, as if this was the universal way in which dementia was experienced. The lack of understanding and the stigma attached made it difficult for families to keep their relative with dementia included in everyday family life. The fear of embarrassment in a public place still causes carers to remain isolated.

Today informal carers are recognised in law for the roles they fulfil and their valuable contribution to the health and welfare economy. The focus now is on living well with dementia. However, although this development is a very welcome one, it is still not easily achieved.

CRAC Dementia

Margaret passionately believed that carers were the people on whom to focus. They were really the ones needing advice and support. Margaret felt carers should be involved in commissioning services since their understanding of the need was better than anyone else's. Both Margaret and Monica recognised the paucity of training in dementia care and shared my mother's enthusiasm for greater improvement.

I met Margaret around 1987 just after she formed CRAC Dementia (*Council of Relatives to Assist in the Care of Dementia*) with a bequest from the family trust of her dear friend Molly Hollick. Margaret brought together a diverse group of carers. Initially the purpose had been to support other family carers, but members of this group had other ideas and the ability to do much

more. I have to admit being faintly amused by Margaret's choice of name for the group, particularly when abbreviated – CRAC'D.

I joined CRAC Dementia in 1988. We were encouraged by Margaret to speak to various groups, at conferences and later to medical, psychology and nursing students, sharing our personal stories. Many members of CRAC Dementia became active in their local areas, joining committees and pushing forward the need for change.

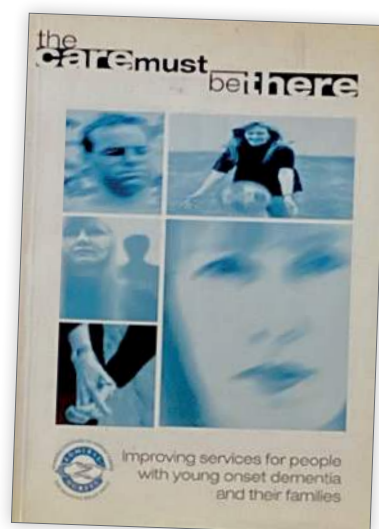
In conjunction with other carers groups, Margaret held a series of three conferences at the Stationers' Hall in the City of London, attended by around two hundred family carers and professionals. During that time, I worked part time with Margaret and another CRAC Dementia recruit, Jane Jarvis, based in Margaret's small office at Athlone House. Athlone House is now a private residence but at the time it housed a specialist residential dementia unit, the Polly Silk Wing, for which Monica was responsible. My experience in event management meant I was able to assist with the organisation of meetings, the training programme and this new venture, conferences. The first event, held on 24 November 1995, was not only an opportunity to bring people from London together but also a brave attempt to encourage professionals to listen to those who understood the challenges encountered better than anyone. Margaret was determined the voice of family carers would be heard. CRAC Dementia was well represented and I spoke about my own experience. The work of CRAC Dementia continued until 2002 when sadly Margaret died at the age of 80.

Not long after having been introduced to the CRAC Dementia group I met another member, Shirley Nurock, who was caring for her husband Leonard, a GP forced to retire early. Shirley recalled that there was absolutely no suitable respite available for her husband, who had been diagnosed with young onset dementia in his late fifties; the only day care centre nearby would not take anyone under the age of 65. Shirley still had school age children who were also seeking support due to their father's dementia. In the early days of the Charity, Shirley was visited by Riverside Admiral Nurse Penny Dodds. At the age of 65 Leonard finally qualified to move into residential care. Shirley continued the work started by Margaret to educate medical students.

At one of the conferences Shirley's daughter spoke incredibly movingly of the time she paid a very special visit to her father at his residential care home. She desperately wanted him to be part of her wedding day though he could no longer walk her down the aisle. She insisted on stopping in her bridal gown to share a private moment with her father. As carers and other relatives, like Shirley's daughter, acquired the courage to relate their personal stories it began to cause a ripple of change in the public's attitude. Sceptical professionals gradually began to sit up and listen – the voice of family carers was finally being heard.

Dementia in various forms also affects younger people. Several CRAC Dementia members were caring for younger people. In the 1980s there was no relevant treatment or age-appropriate provision for those under sixty-five years of age. Little or no specific training existed covering any aspect of dementia care for either unqualified or professional nursing staff, nor general practitioners, although this gradually began to change. Individuals were forced to juggle many problems, often caught between school age children and elderly parents. Many carers now find themselves in this sandwich generation, some forced to give up work to care for relatives.

A 'young onset dementia project' was set up by the Dementia Relief Trust in 1995 to research the needs of people under sixty-five and their families in Kensington & Chelsea and Westminster. The resulting report 'The Care Must Be There' identified the need for flexible and age-appropriate day, respite and residential services for people with young onset dementia, and cited the individual support provided by Admiral Nurses as being particularly beneficial for family carers.



Although I had by then already retired from the Board I was very pleased to learn of the merger in 2020 between Dementia UK and Young Dementia UK. I had always felt it was important that younger people with dementia should be appropriately recognised, and was pleased the Charity had always acknowledged the difficulties faced by younger families. After several years of collaboration, it was agreed the charities Dementia UK and Young Dementia UK would merge. In November 2020 the two charities created a unique partnership to support those with young onset dementia under the Dementia UK name. In 2022, Dementia UK's first Consultant Admiral Nurse for Young Onset Dementia was appointed.



A new venture

Supported by the Joseph Levy Foundation

Training Programme – Carers of the Elderly

Early in 1988 my mother Ninot joined my brothers, Peter and Lawrence, and me on the Board of the Joseph Levy Foundation, the charitable trust established by my father. By this time my father was no longer able to attend meetings due to the effects of the dementia with which he had been diagnosed.



As a result of my father's illness, my mother had identified an overwhelming need for the provision of specialised training in dementia care and was eager to find a solution. That same year, after discussions with Monica Greenwood and Margaret Butterworth, the Foundation supported a project to establish a training programme for unqualified care staff working with the elderly.

The training courses were to be held in the old day hospital Caenwood Lodge located in the grounds of Athlone House, in Hampstead. Having acquired the use of this dilapidated, empty outbuilding, Monica received professional advice from grateful relatives to ensure the building could become fully functional. The interior was cleaned and painted; even carpet tiles were gifted, although Monica insisted on laying these herself.

Monica met Jenifer Newman, who was running a multi-disciplinary course about geriatric care at the Middlesex Hospital, when she presented a session titled 'Dementia or Depression'. Jenifer was very interested in Monica's plans and agreed to help run the training courses, which were established in 1988.

'The Carers of the Elderly' training courses proved successful, soon establishing a widespread reputation for the provision of low cost, good quality training. By 1994 over 2,000 participants had attended courses, and a sizeable team of doctors, paramedics and social workers had been recruited to tutor courses. They readily gave of their time, supplemented by a small team of independent professional trainers with the relevant expertise to offer. There was a full time Co-ordinator and Administrator in post to cope with the demand. Though focussed on general care of the elderly, the training included an increasing amount about caring for someone with dementia.



My mother and I were invited to attend the early courses to assess their value for family carers. My mother was thrilled with the recognition the training programme had achieved. It was a very positive start.

Later, when it became increasingly difficult to secure long-term funding, a decision was made in early 2000 for the 'Carers of the Elderly' training programme to become part of the Charity, then called the Dementia Relief Trust. Carole Evans who had taken over from Jenifer Newman successfully led the transfer to the Charity.

After Carole retired, Mike Phillips joined the Charity as Training Services Manager. Mike endorsed the family feel of the Charity, recalling his first introduction to the trainers: *"I got to meet the trainers, it was certainly a feeling of joining a real family"*. Mike recalls his working relationship with this highly talented and motivated group who all played their part at a time when there was little else available. They came together to develop new ideas for the training programme, enhancing the careers of many working with the elderly, especially those with dementia.

There was some overlap between the trainers and the Admiral Nurses who already had an educational role, but they learnt to work collaboratively. Mike also remembers always trying to ensure there was carer involvement on the courses. He reminisced that one of the highlights of his role was the annual Awards Ceremony. I, too, can still remember the powerful emotions it evoked in us all. The Patrons who agreed to attend this special event to present frontline care-workers with certificates and diplomas in recognition of their achievements included Richard Wilson, Katie Derham, Martyn Lewis and the late Leonard Fenton, with trustees Liz Anderson and David Brettle. The time they gave to attend this very special event was very much appreciated.

The one lasting memory many took from these Awards ceremonies and early Admiral Nurse Forums is the story, always so beautifully relayed by trainer Danuta Lipinska. There are varying versions of The Star Thrower, published in the 1960s by Loren Eiseley, which describes how sand-stranded star fish are rescued and thrown back into the sea. It illustrates the importance of understanding that even if you can't save everyone in the world, you can still make a difference.

Sir Martyn Lewis CBE – Patron from 1997



At the time we met Martyn was a television news presenter and journalist. He anchored both ITN and BBC News bulletins between 1978 and 1999. In 1997, not long after the Dementia Relief Trust was launched, he became one of our most active Patrons. Martyn has spoken in the Foreword about his involvement with the Charity; he would open bazaars, receive cheques, give Christmas readings at the annual Carol Concert, and most importantly later he would tell the story of his family's experience. Our requests for his attendance were rarely refused. I will always be grateful for his support during those early years.

David Brettle – Trustee 2006-2015

David met Monica Greenwood when he joined the North West London Mental Health NHS Trust as HR Director in the early nineties. David advised on the newly established Training Programme 'Carers of the Elderly' and facilitated the Awards ceremonies for several years. David reflects: *"It was an incredibly humbling experience. They were fantastically uplifting events."* When the training programme became an integral part of the Charity, David took over the Chair of the Advisory Committee from Monica. He joined the Board of Trustees in March 2006, where for the next nine years he used his experience to offer guidance on NHS matters and HR support to the Charity.



Difficulties facing families

There were so many families, like ourselves, desperately seeking information and searching for answers. It was hard to know quite where to turn. A few charities or local centres supporting elderly people already existed, although not many focussed solely on dementia.

Charities began emerging within a short space of time as my own family's interest in dementia increased. Alzheimer's (Disease) Society was probably the first charity, established in 1979 by a small group of family carers endeavouring to improve the lives of others.

Alzheimer's Research Trust (now Alzheimer's Research UK) was established at a similar time to the Dementia Relief Trust (now Dementia UK) in 1994/1995. Another, Age Concern, had also grown up in the seventies and after merging with Help the Aged in 2009, became Age UK, focussing on the needs and interests of older people generally.

Another charity developing services for carers, although not specifically for those caring for someone with dementia, was established in 1988: Carers National Association. Carers UK, as the charity is now known, originally set up local carers' centres around the country.

I recall an excellent organisation called Crossroads Care, that had a branch in Camden, which provided respite for families.

There were a few other small locally based initiatives, but it was then, as it remains today, still very much a postcode lottery.

There were few suitable day care facilities able to properly accommodate those with dementia. There were residential homes offering respite and long-term care, but they too lacked specific knowledge or training. Many who were willing to accept dementia patients were often forced to relinquish care after a brief stay since the unqualified care staff did not possess the skills to provide appropriate care. Sadly, even today I am not aware of any current mandated requirement for accredited training in dementia care. There are now many experienced trainers and several pockets of excellent practice for learning with the focus on those with no previous qualification.

"It's the whole journey, it's the whole family. We didn't just work with one identified carer but the whole family unit"

**Sifiso Ndlovu
Agbetorwoka**

At the time, the lack of any adequate training prevented a clear understanding of the condition, which resulted in further anxiety and disruption to the lives of these families already broken and forgotten.

I began to look seriously at where help was most needed. I encountered many dedicated people and was immensely encouraged by their infectious enthusiasm. It felt as if the country was suddenly beginning to wake up to the fact that, with a rapidly ageing population, dementia not only existed but could no longer be ignored. It certainly seemed more than a coincidence that so many new initiatives were emerging at the same time. This period of change was to prove a real opportunity to make headway. My father had always supported those less privileged in society and had the foresight to create a charitable foundation to support the many causes which touched his heart. He led by example, showing us that giving was not all about money; personal contributions can be given in many different ways.

"Families are often seen as a nuisance, so it was just really refreshing to come in and the families, carers were the important people – just as important as the person with dementia"

Debbie Hawkins

Joseph Levy CBE BEM



Joe – the businessman

My father Joseph Levy was one of an intrepid group of property developers who worked towards rebuilding London in the 1950s and 60s following the

Second World War. Joe was naturally sociable; he enjoyed entertaining, he loved dancing and was well known for being the life and soul of the party. He would describe his success as being due to a large amount of hard work with a little bit of luck: I would often remember those words which gave me the will to continue when the Charity was experiencing difficult times. He genuinely enjoyed life, believing that you only get out of life what you put in. In spite of his many accomplishments he was above all a family man, spending time with his grandchildren after his retirement.

“When I started, I wanted to be successful, but no matter how brilliant someone is or what knowledge they have, luck plays a big part”

Joe Levy



Joe – the philanthropist

In later years Joe focussed his attention on his charity work, furthering the goals of the charitable foundation which he founded in 1965. He was awarded the MBE in 1976, elevated to CBE eight years later, for his dedication to charitable causes. The Joseph Levy Foundation has funded many charitable organisations over the years and was instrumental in the establishment of the Dementia Relief Trust, as Dementia UK was called when it was first set up.



Ninot – the wife – the carer

When my father became ill in the mid-80s, we were just another family trying hard to understand what was happening. It was possible my father, and indeed my mother, had been struggling for a while before my brothers and I fully understood and were able to come to terms with the reality that something was wrong.

Acceptance of a diagnosis of any form of dementia will always be difficult, so dismissing the early warning signs is easier than addressing the reality. I had been aware of subtle changes in my dad after an earlier operation when he had spent several weeks in hospital. I have since learnt that any such trauma may advance the onset of dementia.



My father had certainly become more forgetful and confused. Never normally at a loss for words, he began finding conversation difficult. Whilst never the most patient of men, he was becoming more frustrated and easily agitated. He often seemed unusually nervous and frightened, almost childlike. I later learnt these were early signs of dementia. As life became ever more tiresome my mother sought professional help, eventually finding her way to Monica Greenwood, mentioned previously. Monica diagnosed my father with early stage vascular dementia when he was in his mid-seventies.

My father soon acknowledged he was ill, he seemed to feel this was acceptable. For a brief period, my parents had a more settled life, though sadly this was not to last for long. Due to the lack of information available, none of us foresaw what lay ahead and for a short time we were lulled into a false sense of security. We could never have predicted the difficulties which were to follow in the ensuing years, nor the toll my father's illness would take on us all, particularly my mother. We had no idea how long this situation might last. I've often reflected, however, that maybe we were fortunate to be so blissfully naïve and unaware of what the future held.

Similar to all family carers whose partners have received a diagnosis of dementia, my mother's life would never be the same again and this cannot have been easy to accept, particularly since she was still very active during her seventies. In time she had to give up her independence and everything she had grown to love about the years she had been married to my father: a busy social life entertaining their many friends, travelling, and the enjoyable family holidays at their home in France. This good life would gradually diminish, to be replaced by one which was to become increasingly isolated, as many friends withdrew. My parents' lives altered dramatically, it was almost as though they were no longer a couple, it was as if my mother had lost her identity.

The family was grateful that Nin and Joe were financially secure and were able to remain at home together for the majority of this time. My mother coped as best she could, and we all offered our support, but this was unlike anything we had previously encountered. It differed dramatically from a physical disability where one can continue to communicate and share responsibility for important decisions. When a person has dementia, it no longer becomes possible to share your thoughts. All decisions become the carer's sole responsibility.

It is now widely understood that family carers are the last to accept they too require support and in this respect my mother was no different. I noticed she began to pay less attention to herself, seeming to gradually lose interest in her appearance. This was unusual for someone who was always so well-groomed. One day, for example, I met her for lunch and arriving late, which was equally unlike my mother, I noticed she was wearing odd shoes. I never remarked on this as I know she would have been mortified.

Although it is now such a long time ago there are dates you never forget: 29 January 1986 was my father's 80th birthday. I dropped in to my parents' home on the way to the small party that had been arranged for him. He was in a terrible state, as was my mother; she was unable to calm him. He seemed unclear as to what was happening. I realise now he was merely frightened and confused since he was not able to recall being told of the occasion. I remember feeling thankful we had cancelled an earlier suggestion to hold a larger birthday celebration – it was clear he would never have coped. I stayed with my mum to prepare for the evening, but when helping her into her skirt, it almost fell to the ground. As I pinned it up securely I noticed how much weight she had lost.



This was the crucial moment at which I slowly began to understand the effect my father's illness was having. I had never really thought of my mother as a carer but I realised then that she had for so long silently and uncomplainingly carried this burden.

By then in her mid-seventies, my mother was no youngster but she was still very capable, though becoming exhausted, worn down both mentally and physically by the repetitive day-to-day routine. As my father deteriorated the care my mother was able to provide was compromised; even qualified professionals did not possess the knowledge or understanding required yet family carers were expected to cope. It was disturbing for us all to watch him helplessly withdrawing deeper into his shell. No-one offered any explanation on how to cope when he constantly followed my mother around or asked the same questions repeatedly. These may seem like minor problems but multiplied many hundred times a day it can wear down anyone's patience.

As my father's illness progressed the family found the lack of information available extremely frustrating; it certainly would have been helpful to have known even a little of what I learnt subsequently and for my mother to have had the benefit of an Admiral Nurse. Having personally experienced the challenges, one easily recognises the difference the professional support of an Admiral Nurse can make to the life of a family carer. Seeing the difficulties our mother faced on a day-to-day basis led us to

move the focus of the Foundation's support from education and training to consider how we could offer more direct support to carers and their families.

One piece of useful advice I picked up was to resist from engaging in any form of argument which was liable to cause further anger and frustration. My father and I often had strong exchanges in the past, so it wasn't easy to refrain from arguing with him; however this seemed different. I learnt on one of the courses I attended that confrontation could only lead to more upset. I would never win! It made me feel somewhat helpless but at least I managed to alleviate further unnecessary conflict.

We all became more accepting of the steady deterioration of his mental ability. As our understanding improved we began to accept that his unruly behaviour was due to his illness, though it was still upsetting to watch the changes occur. At least after a sustained period of frustration his aggression gradually receded, and he became almost unrecognisable, a far quieter, gentler soul.

I had always associated dementia as a purely mental condition so I was unprepared to see my father change so much physically. As his illness progressed and I learnt more, I began to understand and identify certain familiar features: an anxious look or that blank expression you see on the faces of many people with dementia; I started to see these characteristics in my own father.



The onset of dementia is usually a relatively slow process, except in rare conditions such as Lewy body dementia where it can be reasonably rapid. In most cases awareness of the condition may be delayed for several months, even years. Many who begin to realise they are developing memory loss can introduce undetected coping strategies which prevent recognition by those close to them. I believe this was so in my father's case.

It is hard to pinpoint when anyone's dementia actually starts, and this was very much the case with my father's illness. I discovered like many that there was a time, probably the best part of two years, when we were a little unsure what was happening. Much of his early frustration and confusion was blamed on old age. I estimate his illness lasted a minimum of seven or eight years. My parents travelled to their granddaughter's wedding in Israel in December 1985, by which point his condition had greatly deteriorated. The journey itself had been challenging and he became very disorientated in a strange place. My mother could rarely leave his side. As described earlier, a few months later in January 1986 he was reluctant to join the celebration for his 80th birthday. This again was disturbing to experience. Watching a video from Christmas Day 1988, although surrounded by family, when my mother bent down to speak to him there was absolutely no reaction. It is at least reassuring to see that he was included for as long as he was able.

Some may be surprised to learn that the most upsetting period of my father's illness for my mother was when she had no option but to move him into residential care. This was partially due to the increased pressure on my mother, but my father's health had also deteriorated since he had broken his hip in a fall, which had affected his mobility. One might have thought that she would have welcomed this newly found freedom, but, like many carers, this was for her the hardest time of all, since she had always vowed never to place him in a home. In spite of the fact that he was well looked after she was never really able to come to terms with her failure to continue caring for him. She found it very hard to forgive herself and was often

overwhelmed by guilt. We encouraged her to space out visiting times and to allow some time for her own respite, but she found it so hard to overcome these feelings. As with many carers my mother found it hard to contemplate a life for herself while her life partner was still alive, in spite of the fact they could no longer communicate. Sadly my father died less than six months after this move, never having regained the ability to walk.

I have often reflected that this was really the time my mother would have benefitted most from the expertise and professional understanding of an Admiral Nurse, who would have been able to help her acknowledge the inevitability of these difficult decisions during this deeply distressing time. It is hard to know how to grieve for someone you have already lost some time ago.

It's not easy to explain the feelings experienced when a person with dementia dies. 'Living bereavement' is the term used to describe the carer's experience of loss when no longer able to communicate though the person is still alive. A carer can have great difficulties readjusting to normal life. Their lives have a unique focus for so long; it is an increasingly lonely existence and families often no longer live nearby.

My mother took some considerable time to come to terms with the loss of my father even though he had for some while lost the ability to communicate. We had not anticipated the length and severity of his illness, which had made it even harder on my mother. I had no idea my mother would react in this way, but once again there was no one to explain, no one to help us understand; like so many others we were left to fathom it out for ourselves. Being able to depend on a specialist like an Admiral Nurse to guide one through this process would have been invaluable. Admiral Nurses can support families through the most challenging times; even after a move to residential care and during the final stages of the illness.

Dementia doesn't always have to be grim

Admiral Nurses play an important part in helping carers create coping strategies to come to terms with the pain and loss they experience when a relative is diagnosed with dementia. They recognise there can be an upside of being a carer, not least the humour that seems to help carers through the darkest times – humour often helps to maintain normality in what would otherwise be a rather dismal life. These specialist nurses offer carers an opportunity to speak honestly, listening without judgement.

I often felt helpless observing my father becoming increasingly disturbed. One day he was watching his beloved Arsenal playing on the television but he was no longer able to follow the format of a game he had first watched from the terraces when he was seven years old. It was upsetting to see what his life had been reduced to, but we managed eventually to see the funny side and berated the officials who he blamed for changing the rules. Amongst ourselves we joked about how we saved money on occasions such as birthdays, when the only present fully appreciated was a giant bar of Cadbury's Dairy Milk! Sometimes it was hard to avoid feeling disrespectful, but it was always my understanding that we made every effort to laugh with him and never at him.



There is no doubt it is hard to erase the particularly upsetting, more hurtful moments, such as the time my father no longer remembered he had a daughter. However, understanding this was the dementia, not the person, made it much easier to accept. Admiral Nurses convey this to carers, explaining it is understandable to feel angry and resentful, but that this should not prevent occasional elements of humour gently creeping in. These distracting moments are a way of retaining one's sanity, creating some form of normality in a carer's otherwise unpredictable world.

All families react differently but we tried our best to retain a sense of humour. There were amusing incidents with the grandchildren who related well to their grandfather's now more juvenile humour! He had always had a great affinity with children, and like many people with dementia he did not seem to feel threatened by them in the same way as he was by adults. I recall a Sunday lunch when my father encountering coordination problems had difficulty keeping the peas on his plate. Stifled giggles soon generated into loud laughter as in no time our children had joined in the game. Peas shot across the dining table like miniature flying saucers. As hard as the adults tried, we could not prevent broad smiles appearing on our faces; it was a wonderfully happy but brief moment in time, offering an all too short opportunity to forget the misery.



Joe's Grandchildren

My children were a relatively young age, between ten and early teens, when the first signs of my father's dementia emerged in the 1980s. Looking back, I now understand that they, too, suffered their own loss, that of a popular grandfather who had been so much a part of their early lives.

When asked, my children explained they had not grasped the seriousness of his illness. They saw how their grandfather behaved differently, unable to hide his confusion and anger at times. They were too young to appreciate the impact caring had on their grandmother, who bravely hid her feelings from them. It did upset me when they began to refer to him as 'grumpy' Grandpa, though this was probably an apt description at that time, it was so unlike his true character.

"From a child's point of view a grandparent comes across as quite old, you associate it with age as opposed to an illness, many stories were repeated and he became very slow"

Mark

"I don't have any recollection of dementia at the time, he just became more withdrawn, more distant. You had to shout a bit louder. Repeat yourself a bit more"

Jamie

I understand now that every family member is affected in their own way. Many carers are unable to recognise or acknowledge the effect it has on them, often not recognising they need help. It was some time before any of us realised how much we were struggling or that his young grandchildren too were experiencing a sense of loss they didn't fully understand.

The duration of this cruel illness means very gradually small changes occur and over many years one can do nothing but watch the slow deterioration of the person you once knew. It is difficult to describe the effect this has on individual members of a close family. I found the inability to communicate the hardest; it felt disloyal having discussions behind my father's back, even if we were considering his welfare. We continued to learn as we went along, picking up tips wherever we could, there really was no other way. How can you prepare, if you have no idea what you are facing?

My father died on 18 December 1990. It was strange how so soon after his death we were able to remember the person he had once been. The family spent Christmas Day together reminiscing. The memories came easily. Having time to reflect on the past few challenging years proved a surprisingly therapeutic experience.

"Grandpa was fun, he was the joker and made you feel happy. Mum explained that Grandpa couldn't remember things and that he might behave differently and get annoyed. I don't think that I would have known the word 'dementia'"

Katy



Move to focus support on the carer – understanding the illness

Observations we made throughout my father's illness improved our understanding of dementia, giving us the courage to speak out in an attempt to educate other family carers. With the Foundation's backing, the family started to focus attention on how we could improve the support provided to other families also caring for someone living with dementia. Having witnessed the effect my father's illness was having on our mother, we were convinced that this was a neglected area of need.

There were numerous discussions and in late 1988 the family sought a further meeting with Monica Greenwood to discuss options of how we might extend the Foundation's support. Several ideas were raised; we rejected any form of research as we were keen for a more practical approach. As the children of someone recently diagnosed with dementia we now

understood the effects on all members of the family and were very much in favour of the proposal for a specialist support worker, possibly a nurse, to work with families affected by dementia similarly to the way Macmillan Nurses help those with cancer.



"If you don't know what to expect how do you prepare for it?"

Jane – Joe's daughter

"When he was diagnosed we didn't fully understand what that meant"

"It's so difficult not knowing how the person is going to change"

Peter – Joe's eldest son



Strengthening support for family carers

The Levy family was excited about the prospect of the Foundation's involvement in a project which would not only raise awareness of dementia, but offer a lifeline to so many other families struggling to cope. I was very keen to be part of this new idea. Although the Foundation Board was small, trustees were regularly involved beyond the simple act of distributing funds, a tradition learnt from the example set by my father. As trustees of the Foundation, we were determined that we would make a real change in this area of unmet need to follow on from the Foundation's support for the Carers of the Elderly training programme.

Monica already had ideas of how this could be achieved. She planned to form a steering group in order to engage the assistance of other professionals. Establishing a pilot project would prove whether the idea would be viable.

The first official notification of a forthcoming 'Alzheimer's project' can be found in the minutes of the Joseph Levy Foundation Board meeting held on Tuesday 17 January 1989 at 11 Waterloo Place, London SW1, stating that the Foundation was considering a proposal to provide support for families. Finding this statement as part of the research for this book reminded me that Alzheimer's was often used as an easily recognisable way of describing any form of dementia. The term dementia was not yet fully understood or accepted.

The difficulties in gaining wider support to set up a project of this kind are illustrated by the postponement of the original start date for more than a year. This was recorded at another Foundation meeting, held on Tuesday 2 May 1989, where it was noted that the start of the Admiral Nurse Project may be delayed until late 1990. However, the Foundation's Trustees were fully committed, and had already allocated funding for the next three years.

We should have realised that this delay was an indication of the roller-coaster ride on which we were about to embark. I don't think any of us had fully appreciated the problems surrounding a project of this nature. I have to admit it was difficult to keep up with the changes within the National Health Service, which was undergoing a period of significant upheaval. It was a challenging time because of the frequent revision of both boundaries and staff, due to substantial NHS reforms announced by the Conservative government in 1990, the same year the Project began.

"It isolates you
from your friends"

A family carer

"You're limited with what you can
do; you can't really leave someone
with dementia alone"

A family carer

"If nothing was done to
help the relatives then
they would collapse and
become patients"

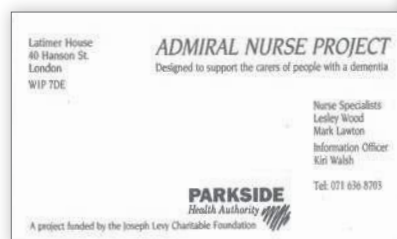
Monica Greenwood

The Admiral Nurse Project 1990-1993

Planning begins for the pilot project

There were professionals who had difficulty grasping this new concept of creating a specialist nursing service primarily to support family carers. I was very grateful to those who had a clear vision and understanding of the Project's intentions. Monica admitted that, without the support of colleagues, it was most unlikely any new project of this kind would have succeeded, even if funding had already been secured.

It is therefore very important to acknowledge the collective contribution of the many professional staff who gave up so much of their time to support the Project. Some thought the Project had great potential. When I tracked down Erville Millar, who had been Director of Operations in Bloomsbury at the time of the Project, he told me he thought the idea was brilliant, explaining: *"It just seemed such a sensible idea."*



"The Admiral Nurse Service is a service to be valued, appreciated and purchased"

Peter Carter

Dr Peter Carter OBE



Peter Carter trained as both a psychiatric and general nurse. In January 2007 he became General Secretary and Chief Executive of the Royal College of Nursing (RCN). We met very early in my dementia journey, and he became a loyal friend and supporter of Admiral Nursing, having the foresight to realise the real value of the service when others doubted it. In the 2006 New Year's Honours List Peter was awarded the OBE for services to the National Health Service.



From the late 1990s Dr Peter Carter was Chief Executive of the Central and North West London Mental Health NHS Trust, and as a keen supporter of Admiral Nursing he helped establish some of the first Admiral Nurse teams. There are many who feel progress has not been as swift as it might have been but not everyone fully appreciates the complications which arise when establishing services. Peter recently told me: *"It wouldn't have been unreasonable to think that this is going to make a huge impact. I was hoping it would really gather traction."*

Stumbling blocks soon emerged, the main one being that many professionals opposed the idea of offering support to the family carer, rather than to the person with dementia. Monica's professional team, Margaret, myself and other CRAC Dementia family carers stood our ground. We worked hard to explain the concept that we believed supporting the family carer would make a significant difference to the person with dementia, as well as improving the health and wellbeing of the carer. There would be a dual impact, leading to positive outcomes for both.

Monica continued to explain endlessly that these specialist dementia nurses would safeguard the National Health Service by preventing family carers from falling ill and becoming in-patients themselves. The more we persevered, the more they listened. The plans for the Project slowly began to take shape. We were not to be deterred, becoming more determined than ever to succeed in our quest to place 'Admiral Nursing' on the map.

"It was wonderful that this little idea had grown. It had taken a long time to grow but it was growing, and it was a good thing"

Monica Greenwood

"These were exciting times"

Erville Millar

At some point around this time Monica, Margaret and I visited the offices of Macmillan, which in 1989 changed its name to Cancer Relief Macmillan Fund. I recall that this, together with the introduction of Comic Relief in 1985, had influenced my original choice of name for the Charity – 'Dementia Relief', though it was later extended to the 'Dementia Relief Trust'. I was impressed by the size of the Macmillan charity and remember wondering if our charity would ever grow to that size. Everyone we met was most helpful and encouraging, whilst also being honest about the difficulties and pitfalls inherent in setting up such an innovative and independent nursing service.

Although it has never been officially substantiated it seems the idea for a carer focussed professional role originated from discussions amongst family carers. The concept had been mooted for a while before my family came on the scene, but we were privileged in bringing these ideas to fruition.

The suggestion that a professional nurse model might best fulfil this specialist role was well received by family carers who had been emphatic that the professional identified should have the relevant skills to support families, both practically and emotionally, as well as possessing the expertise to provide advice and training in dementia for other professionals.

Finding a name

I had not realised the real reason it was felt necessary to seek an alternative to the term 'Dementia Nurse' was due to the stigma and negativity attached to the condition. The Foundation was invited to put forward ideas, but when we found it difficult to find anything suitable I decided to engage the help of my immediate family.

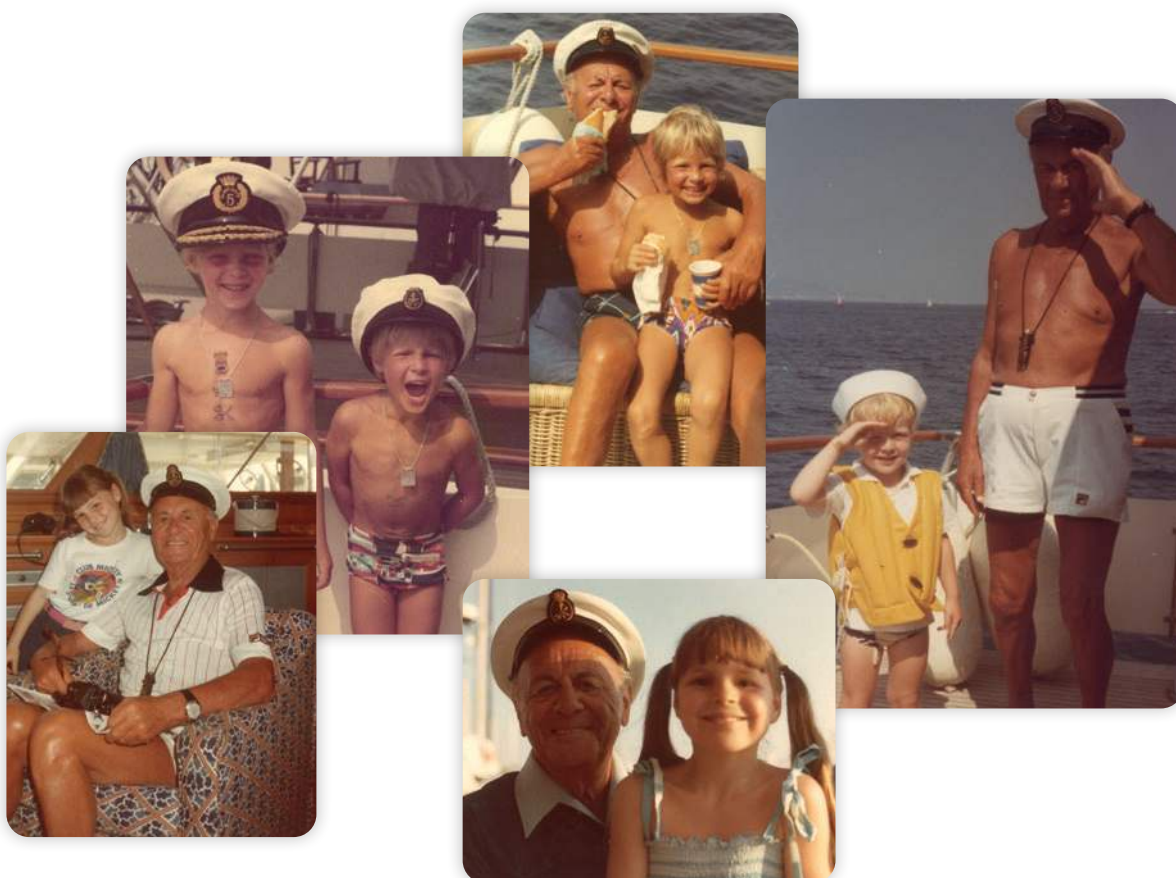
One evening when we were out enjoying a Chinese meal, I asked the children for ideas. I was surprised how genuinely enthusiastic they appeared. After a lengthy discussion they came up with a proposal. My father, a keen sailor, was known as 'Admiral' to his French friends, for whilst on holiday he was rarely seen without his Captain's hat. Naming the nurses has subsequently become an engaging part of the story. I am sure my father would have derived great pleasure that it was his grandchildren who identified the name in his memory for a service which was to help so many others.

The name 'Admiral Nurse' was enthusiastically received. It was agreed and officially noted in the minutes of the Joseph Levy Foundation Board meeting on Tuesday 12 December 1989.

"If I had a pound for every time I had to explain where the name came from I'd be a wealthy man!"

**Mark Lawton –
The first Admiral Nurse**

It should be mentioned that although the name had been chosen in good faith, in our naivety we had not foreseen the problems which lay ahead. Over the years various Admiral Nurse teams have received endless enquiries about insurance as well as numerous questions relating to the Navy. I was even once asked the name of my father's ship when a serving Admiral! As one of his grandsons commented: *"In spite of his nickname he had absolutely no naval experience, which in many ways was typical of Grandpa."*



Admiral Joe



From the beginning carers were curious why the name 'Admiral' had been chosen. Apparently, this remains one of the first questions asked by carers when meeting their Admiral Nurse. Families have always seemed to welcome learning more about the history of the Charity. I have been told that it is of great significance to many that the original idea came from carers with a shared experience and that the Charity was established in memory of a family member with dementia, offering reassurance that the problems faced were both fully acknowledged and understood.

In the end the Project started almost on time. A report from Monica Greenwood to the Joseph Levy Foundation states the Project began in April 1990 with two Admiral Nurses, an Information Officer and a Researcher who would focus on evaluating the Project. This may have been a little optimistic, but we achieved it in the end.

“Every charity should always remember its roots and foundations and its history because that’s got to be the core of everything a charity does”

Mike Phillips – Training Services Manager, Dementia Relief Trust

Setting up the English National Board's Multi-Disciplinary Course on 'Dementing Illnesses' (ENB N11)

The next step was the creation of a multi-disciplinary course for 'dementing illnesses' at the Bloomsbury and Islington College of Nursing and Midwifery. Once again it appeared we were pioneers. No official training course specialising in dementia care was known to exist. The English National Board course (ENB N11) was established so that all participants could advance and deepen their knowledge and understanding of people with a 'dementing illness'. It addressed the issues and problems facing family carers, whilst considering the role of the professional in the relationship. It was open to all professionals involved in the care and management of people with dementia.



This new course was planned to complement the work of the Nurses. Ron Isaacs, the newly appointed Course Tutor, worked closely with the original Admiral Nurses to finalise details of the programme. It was a prerequisite for Admiral Nurses to have completed the ENB N11 course. As one of the

pioneers of Admiral Nursing, the first Admiral Nurse Mark Lawton not only attended the lectures but went on to actively teach on the course. Retired Admiral Nurse Dave Bell also recalls attending and later teaching on the ENB N11 course and reflects here on how difficult it was to find any form of information about dementia; his comment "*there were no books on the shelf*" refers to the lack of availability of any suitable reference material.

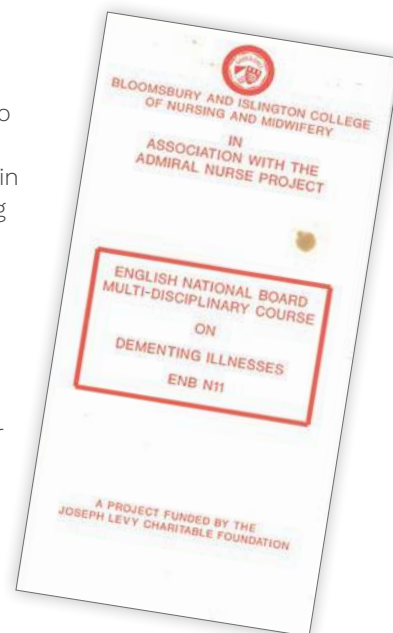
At the same time Margaret Butterworth continued in her insistence that personal experiences from family carers should be included as an integral part of the programme. The value of these personal contributions was soon recognised and, due to their popularity, these sessions were extended to an entire day. I attended several of these Carers' Days, describing my own experience of my father's illness and the effect his dementia had on my mother and other members of our family. I was surprised to discover how little the students actually knew about dementia, and it was very

rewarding to be able to reach out to help the course participants gain a better understanding of what living with dementia could be like. I still find it hard to comprehend that, over thirty years on, dementia is not yet a mandatory module for every nursing student in the country, or that not all students experience dementia-specific placements. People with dementia, and other conditions which increase vulnerability, can experience greater health inequalities. Improving education for all health and social care staff, including nurses, would help achieve a parity of service for all vulnerable patients.

This 24-day ENB 11 course was spread over a period of three months. It was funded by the Foundation in conjunction with the Admiral Nurse Project. The course ran three times a year and initially both this new course and the nursing project, which were still in their infancy, attracted considerable interest and national publicity. The original Course Tutor, Ron Isaacs, was invited to speak at the Royal College of Nursing Conference held on 18 October 1990. Ron continued to run the course for a further few years until he sadly died prematurely. Hopefully he will be remembered for the active role he played in the advancement of dementia care.



Unfortunately, a few years later the English National Board (ENB) was disbanded, curtailing all their accredited courses. In 1995 Moira Sugden, who had been working at Middlesex University since 1991, became interested in taking over the running of the course. Moira had previously qualified as a mental health nurse in 1980 after being attracted to working with dementia patients during an early placement at Friern Hospital in North London.



As knowledge of dementia advanced, the original ENB N11 course would become the first module of three included in a new Advanced Diploma of Dementia Care. It was reassuring to learn that, because of an increased demand for more detailed knowledge in dementia, not only was the original course to survive (albeit in a different form), but it was soon to be accessible to students in various centres around the country. As far as I am aware this diploma still exists today, a wonderful legacy for all those who originally contributed.

Although the Project was generating much local interest, the idea to focus on the carer and not the patient with dementia continued to be questioned. The stubborn failure to acknowledge the impact on the family carer was frustrating to put it mildly. Even some highly regarded professionals seemed unable to grasp the long-term consequences for families. Mark Lawton, the first Admiral Nurse, had his own way of approaching the sceptics: *"Don't take no for an answer." "You've got to be a little avant-garde; you have to be prepared to stick your neck out, fight for things you know are right, not go along with the status quo."*

It was hoped that Admiral Nurses, as qualified specialists, might begin to change people's perspective on dementia and, by supporting individual carers, families would gain a broader understanding. There was a desperate need to improve the lives of those living with dementia and we were determined to play a part in making this happen.

Creating the Steering Group

In 1990 Margaret Butterworth, Isobel Hunter, another former carer and member of CRAC Dementia, my mother and myself were invited by Monica to join the steering group she was establishing to monitor the pilot project. Monica was very aware that it was becoming increasingly recognised that carers should be included. She also engaged the support of other professionals. Barbara Dicks, a Senior Nurse working as the Regional Palliative Care Nurse at North East Thames Regional Health Authority, was one who offered her help, recognising that dementia was a terminal condition and the care of a person with dementia, especially in the latter stages, requires specialist end-of-life nursing care. Another person I remember was Sarah Whitfield (Davies), who at the time was a senior nurse manager for the care of the elderly. Sarah later attended the launch of the Charity with her husband.

A few original steering group members continued on the interim management committee, before joining the newly formed Admiral Nurse Advisory Committee known as ANSAC in 1994 when the Charity was officially established. This committee took over responsibility for the overall development of the Admiral Nurse Service. As a trustee of the new charity the Dementia Relief Trust, Monica continued as chair of this newly established committee.

Recruiting Admiral Nurses

One of many obstacles to overcome at the start of the pilot project was recruitment of the nurses. The first Admiral Nurse applicants, operating within the NHS, were offered a fixed-term contract for three years. If the pilot proved successful, their roles could continue. It became evident that few were prepared to take this gamble as only one of the two appointed candidates appeared on the first day. It took two to three months to find a replacement willing to join the Project.

Mark was therefore delighted to finally be joined by another Admiral Nurse, Lesley Woods, but sadly it wasn't long before she moved abroad. The next nurse to be appointed, Ann Medina, did not have the same background. She was however an experienced community nurse and better qualified than any of the other applicants with a mental health background.

During the first few years recruitment of nurses proved equally difficult. However, much has since changed. As recognition of the Admiral Nurse role has grown, development has become easier. The support provided by the Charity, now known as Dementia UK, and the career structure now available within Admiral Nursing, offers an attractive career choice for anyone wishing to specialise in dementia care. Apparently there is now always an excellent choice of applicants.

**PARKSIDE HEALTH
AUTHORITY
MENTAL HEALTH UNIT
ADMIRAL NURSE PROJECT**

**SPECIALIST NURSE
'G' GRADE**

**Salary £15,320 - £17,735 plus £1,700
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We require a nurse to join an innovative nursing service that has been developed specifically to meet the needs of carers of people with a dementing illness. The Admiral Nurse Project has been running for 18 months. A model of care has been developed that goes beyond the bounds of the more traditionally recognised nursing services: the postholder will be a member of this team until the expiry of the charitable funding in April 1993.

The post will be based in the heart of London's West End: the area covered is that of North East Westminster comprising St John's Wood, Marylebone, Mayfair, Soho and Covent Garden.

The postholder will visit carers at home, provide specialist advice for other agencies and professionals, assist in teaching, and help further the Admiral Nurse Service.

The successful candidate must be either an RMN or a health visitor with a recognised qualification and experience in community and elderly health care, with a particular understanding of dementing illnesses.

He/she should have good interpersonal and counselling abilities and will provide the information, support, and skills required by carers.

The postholder will be encouraged to attend the ENB N.11 course "Care of People with Dementing illnesses and their Carers," organised by the Bloomsbury & Islington College of Nursing & Midwifery at the Middlesex Hospital.

For further information, please contact Mark Lawton, Admiral Nurse Project, Latimer House, 40 Hanson Street, London W11 (071-636 8703).

Application forms obtainable from
Personnel Department, Mental Health Unit,
Central Middlesex Hospital, Acton Lane,
London NW10 7NS. (081-453 2755)

Closing Date: 22nd January 1992
Interview Date: 11th February 1992.

Parkside Health Authority aims to be an Equal Opportunities Employer and we particularly welcome applications from disabled people.

The first Admiral Nurse

There is no doubt as to the identity of the first Admiral Nurse, since only one turned up on that first day in April 1990. He was a young man named Mark Lawton from Ashbourne in Derbyshire, who had begun his general nursing training at the Derbyshire Royal Infirmary in January 1977. He qualified as a Mental Health Nurse (RMN) around 1984 and became a charge nurse on an elderly mentally ill unit where the majority of patients had dementia. Like many subsequent Admiral Nurses, he had also previously been a Community Psychiatric Nurse (CPN).

Mark was keen to begin, and was eager to be involved in what appeared to be an exciting project. He fully understood the original concept, explaining: *"I knew my work with carers was equally as important as my work with the patient."*

There were however one or two setbacks that impeded progress initially. Arriving at Latimer House in North East Westminster, there was no office readily available. Mark found a space for himself in what appeared to be the office storeroom. He secured a desk, but finding a phone proved more difficult. It seems he did, however, have a wide choice of filing cabinets!



"I feel incredibly proud and privileged to have been an Admiral Nurse, let alone the first"

Mark Lawton

Although the Project office left much to be desired, it was spacious, and this young man from the Derbyshire Dales couldn't believe it when he sighted the BT Tower from his window. The view from the Charity's current London offices at 1 Aldgate is more impressive.

A further complication to recruitment was the re-grading of all nurses which occurred in the NHS during the early 1990s. Due to the independent nature of the work, and the level of responsibility, the role of an Admiral Nurse had been graded highly by those professionals involved on the steering group. At the time, they were allocated H and G Grades, the higher grade being for a Team Leader post (equivalent to a Band 7 today). It was not easy to recruit to these new posts when offering a limited short-term contract with an unsure future. However, it was necessary to appoint nurses of the highest standard in order to maintain the quality of care provided to families which has since been constant throughout the life of the Service, and still remains a key priority today.

"I don't think it's enough to just stick a label on a nurse and call them an Admiral Nurse. You can easily achieve a target, but they've got to maintain the quality because if you don't you will start to devalue them"

Julia Botsford



Fortunately, as the number of nurses grew slowly, we began to realise those chosen had inherited the same pioneering spirit. Many Admiral Nurses would experience similar difficulties initially. The shortage of desks, telephones and other necessary equipment became an emerging theme as new teams attempted to establish offices. It was though going to take much more to dampen their enthusiasm. Despite the opposition initially encountered, it did seem that these newly appointed Admiral Nurses possessed the character and determination required to take it all in their stride!

The passion for their work that I recognised in many of them is still evident thirty years on. Several had previously worked as Community Psychiatric Nurses, and as CPNs they believed that they had always done an adequate job supporting family carers. This opinion was shared by other CPNs operating around the country and was identified as one of the main reasons Admiral Nurses were viewed with suspicion when the Project was still in its infancy, relatively untried and untested.

When taking up an Admiral Nurse role, many soon acknowledged that the carer required more time than they had been able to offer in their previous roles. The carer could contact the Admiral Nurses directly provided that the person with dementia had received an official diagnosis.

It also soon became clear that it wasn't solely the primary carer who was affected, but, in many cases, the entire family required expert guidance and support. Admiral Nurses are now able to support all members of the family where it is necessary.

The qualities shown by these professionals endorsed the importance of recruiting nurses of the highest calibre, irrespective of cost. It was imperative then, and remains so now, that quality would prevail in order to maintain the required standards for Admiral Nursing to remain a 'Gold Standard Service'.

Expanding the Project Team

Starting work with the Project at the same time as Mark was Kiri Walsh (Prendergast) who had been appointed as the Information Officer, a difficult role to define.

Kiri, who had graduated with a Bachelor's degree in Social Science, hoped to become a social worker but turned her energies to research and was in many ways instrumental in developing the first model of care, working out how to develop strategies. She had been attracted by the innovative nature of the Project and was less concerned about her job title. Since her role included administration, one of her first priorities was to design a leaflet for the Project.



Kiri was apparently also at times referred to as the archivist. She often worked closely with Stella Silvester, the research assistant recruited by Dr Mark McCarthy at the Department of Public Health at University College London, to assist with an evaluation of the Project. Much of the time they also worked alongside Monica Greenwood. Stella later moved on to a career in psychiatric research.

“What an achievement –
to be bringing so much relief
to so many”

Kiri Walsh (Prendergast)

Developing the Service – establishing new teams

Admiral Nurses continued to contribute to the recently established ENB N11 Course, sharing their knowledge and innovative way of working with family carers. These nurses required not only a deep knowledge about dementia, but also the understanding and skills to intervene when people were experiencing severe anxiety and distress. In extreme cases the ability to recognise clinical depression could lead to referral to another professional.

However, many issues not initially considered soon became evident as the Project progressed.

Progress was continually hindered with repeated NHS boundary changes. Monica explained that her notepaper changed yet again when her service became part of North West London Mental Health Trust (South Camden and North East Westminster). She reminded me that although she remained in exactly the same job and location, the borders changed frequently. The ever-changing boundaries in turn brought about a lack of continuity in NHS management. This meant that the promises of one incumbent were not seen as binding by another. Much time was wasted building relationships which could not be sustained as staff moved on. It soon became evident that a more secure partnership agreement was necessary if there was to be a real opportunity to permanently develop the Service.

“One of the difficulties was trying to offer a service to non-patients which I had to justify and convince them of the value of it”

Monica Greenwood

The Joseph Levy Foundation agreed to fund two further nursing posts in Camden and Islington, in addition to those in the original team still based at Latimer House. Sadly, this new team was eventually to be one of our early failures since there was a refusal by the local NHS Trust to sustain support for the Service after the initial period of two years. Monica was furious, as we all were, but a valuable lesson had been learnt and decisions were made to set up services differently to allow negotiation for a more solid commitment by the host trust in the future. We realised that the principle of pump priming (which involved a joint funding agreement for two years between the Charity and the local health trust, after which the funding of the post would become the total responsibility of the trust) was dangerously fragile, often leaving newly established teams vulnerable at the end of two years. Many changes when establishing posts have been made over the years to try to address this issue.

As custodians of the Foundation, the trustees, including my brothers and I, realised that if the vision to continue to develop the Service nationally was to succeed, additional financial help would be required to sustain any sizeable growth. Although the trustees unanimously wished to remain fully supportive and active, it was evident the Foundation did not have adequate resources for serious expansion of the Admiral Nurse model. It was clear additional funding sources should be sought.

In spite of the uncertainty there are many happy memories from this time. Changes occurred, but it somehow felt we were moving in the right direction. Admiral Nurse Mark Lawton recalled: *“In a way it just happened, as if the stars had aligned, everyone in the right place at the right time; from the very beginning it was as if we all belonged.”*



Evaluation of the pilot project

'A Measure of Success'

In April 1991, in the second year of the Project, Research Assistant Stella Silvester, working under Dr Mark McCarthy, produced a paper 'A Measure of Success?'. This was a brief evaluation of the Project's 'Needs Assessment Schedule', which provided a problem-solving tool, enabling the Nurses to identify needs and offer guided interventions.

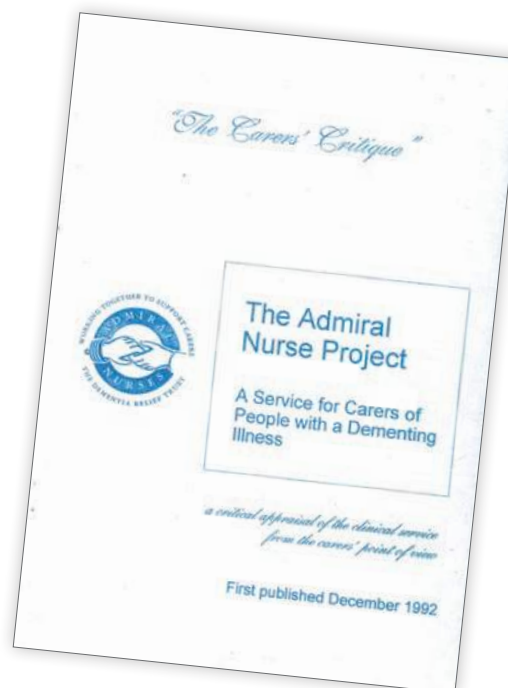
The Admiral Nurses used the Schedule to assess and score the individual needs of family carers, identifying the problems they were facing. This is an early example of how the Admiral Nurses worked with other clinicians and researchers to establish their innovative role. No official guidelines existed for the support needs of family carers. The development of the Schedule received assistance from Professor Irene Higginson, who had always believed in Admiral Nursing.

The 'Carers' Critique' published in December 1992

In 1992 an evaluation of the pilot project was published entitled: 'The Carers' Critique: The Admiral Nurse Project – A Service for Carers of People with a Dementing Illness'. The aim of this piece of work was to appraise the clinical aspects of the Admiral Nurse Service specifically from the point of view of family carers

A brief questionnaire was compiled, and interviews took place with those who had received support from the Service between August and October 1992. The evidence from 'The Carers' Critique' was of overwhelming appreciation of the Service from those who had used it at that time. The evidence confirmed that carers often felt isolated and needed help to understand and accept the condition they faced.

The authors of the report, Jane Jarvis, Jane Jason and Margaret Butterworth, considered the comments and recommended that Admiral Nurse posts be created in each health district in the country.



Evaluation – Dr Mark McCarthy, Department of Public Health at University College Hospital – 1993/94

A formal evaluation was specified in the original proposal for the pilot project, with funding provided by the Joseph Levy Foundation. Research for the evaluation was undertaken by Dr Mark McCarthy at the Department of Public Health, University College London, assisted by Stella Silvester. Although the research identified some key benefits for family carers, the study produced no significant findings and was never published.

Dr Monica Greenwood continued to write regular reports to update the Joseph Levy Foundation on the Project's progress. I'm not sure everyone fully appreciated the problems overcome, or the endless negotiations which continued throughout the Project's term. Success was not inevitable, indeed far from it; the commitment of this small team, supported by Monica and members of the original steering group, often after working long hours, should be acknowledged and their achievement in succeeding in placing Admiral Nursing on the map in spite of the odds duly recognised.

"It's easy to talk to the Admiral Nurse because you know you're talking to an expert"

Quote from the Carers' Critique

"I just didn't know what to do with myself – it was making me ill"

Quote from the Carers' Critique

Medical Patrons and Ambassadors

The trustees of the Dementia Relief Trust considered it was important to identify those from the medical profession who had shown continued support for Admiral Nursing. Over a period of time, a number of eminent medical professionals became Patrons or Ambassadors for the Charity.

Medical Patrons and Ambassadors

Dr Sarah Eagger: At the time a Consultant Psychiatrist and honorary senior clinical lecturer at Imperial College London. Sarah had supported the establishing of the Admiral Nurse teams in Riverside and was one of the first medical Patrons to be appointed.

Professor Irene Higginson OBE: An early supporter of Admiral Nursing, currently Executive Dean of the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care and Faculty Vice Dean (Research). She is also Director of the Cicely Saunders Institute of Palliative Care at King's College London.

Professor David Jolley: Now retired, David was Consultant Old Age Psychiatrist in Wolverhampton from 1995 until 2005. He supported the early Admiral Nurse development in the West Midlands. David was also very attached to his George Melly event T-shirt!

Professor Martin Orrell: Until 2015 Professor of Ageing and Mental Health at University College London. He is now at the Institute of Mental Health, University of Nottingham.

Professor Martin Rossor: Now Professor Emeritus at UCL Queen Square Institute of Neurology, who specialises in young onset and rare dementias.

Professor Bob Woods: Now Professor Emeritus at Bangor University, Wales who worked on an Admiral Nurse evaluation project with Walter Wills.

Professor Charlotte Clarke: Then Professor of Nursing Practice Development and Research, Associate Dean (Research) in the School of Health, Community and Education Studies at Northumbria University. An Ambassador for the Charity's 10th Anniversary Year 2005. Charlotte is now Executive Dean (Social Sciences and Health) at Durham University.

John Libson – Honorary Treasurer 1995–2009

The late John Libson, a qualified accountant, was introduced to the Charity by Peter Levy, then Vice Chair. John joined as the Charity's first Hon Treasurer before the official Launch in 1995. He retired from the Board in 2009 having steered us safely through some very rough seas. Many on the Board including myself were grateful for his calm and steady guidance. John had experienced dementia early on in his own family and understood the benefits which Admiral Nurses could offer. He and his sister Susan Shear became loyal supporters of the Charity.



Planning ahead – *A new dementia charity*

With the successful implementation of the Admiral Nurse Project at Latimer House, the Trustees of the Joseph Levy Foundation were seriously considering how the Foundation might continue to support the development and growth of the Admiral Nurse Service. Due to early teething problems, the Foundation agreed to extend the Admiral Nurse Project for a further year. It was reported in the minutes of a meeting of the Board on 22 October 1992 that there were sufficient reserves to continue the Project from April 1993 to April 1994. Further new teams were already on the horizon so the Board required time to plan for the future.

The Foundation had been very generous, but I fully accepted the situation was not sustainable if we intended to extend the Admiral Nursing Service nationwide. A recurring thought emerged to create an independent charity, which would raise the profile of Admiral Nursing and the necessary funds required for the growth of the Service.

Looking back, none of us fully understood quite what we had taken on. However, we were gathering momentum and were keen to continue, though I have often remarked that if I had fully realised the enormity of the task I might have thought twice before plunging forth into the unknown! I explored the idea of a new charity with my brother Peter to gauge his reaction since I knew it would be important to be assured of his support, both personally and as a fellow trustee of the Foundation. My younger brother, Lawrence, was very supportive, but since he spent much of the year out of the country he would be unable to participate in the same way.

I was encouraged by Peter's positive reaction and appreciated the offer of the use of a small back room located in the offices of his company, Shaftesbury, so that I might start planning this new venture. The office location at Waterloo Place in central London proved extremely practical since the Foundation was based in the same building. I was able to take advantage of the help offered by my brother and the Foundation Director, Dr Sidney Brichto, whilst also accessing valuable administrative support from Sidney's personal assistant, Beverley Taylor.



The Foundation took the initiative and began work to establish the Charity with the relevant charity law professionals. The Board of Trustees was to comprise my two brothers, Peter and Lawrence, Monica Greenwood, Margaret Butterworth and myself in the role of Chair of the Board. Margaret suggested my mother Ninot, who did not wish to join the Trustee Board, be offered the honorary title of Life President in acknowledgement of her past interest and involvement. As reported in the Foundation's minutes of 13 October 1993 the application for official charitable status was noted and after eight long months the charity 'The Dementia Relief Trust' was eventually incorporated on 30 June 1994. It was registered with the Charity Commission on 12 July 1994 receiving the official Charity Registration Number 1039404. The following year we were joined by the late John Libson as the Charity's first Honorary Treasurer.

I was the first to admit to having little idea where to begin but, having not thought about much else over the previous few months, I couldn't wait to get started. It was encouraging to see a deeper understanding and empathy for those with dementia slowly developing. The Foundation was once again ready to play its part.

Early fundraising for Admiral Nurses

I discovered I was able to raise funds for Admiral Nurses via the Joseph Levy Foundation prior to the Charity being officially established so I could take advantage of opportunities which arose. At the Foundation office, with Beverley Taylor's help, a simple notepaper was designed in blue, the Charity's first official colour, with 'Admiral Nurse Service' appearing at the top of the page. Unlike today, when so much communication is done electronically, in those days notepaper including the Charity's registration number was required, while official mail was sent by regular post.

Wellington Foundation Ball

In May 1993, through an introduction to Dr Arthur Levin, founder of the Wellington Hospital in North London, Admiral Nurses together with The Dementia Research Group became the recipients of funds raised at the 14th annual Wellington Foundation Ball. All proceeds from the evening were to go to the care and research of Alzheimer's disease (the term dementia was still not yet widely used).

The event was written up in Hello! Magazine in June 1993 with wonderful photographs of Princess Michael of Kent but sadly the article contained a completely inaccurate description of the Admiral Nurses! This was a good lesson learnt on the inaccuracy of reporting by journalists more interested in the celebrity guests attending, though one has subsequently learnt one can never fully control what is written in the press.

Gala Concert at St James's Palace

I persuaded a few friends to join a small committee chaired by the late Morella Kayman, one of the original founders of the Alzheimer's Society, as we had worked together on similar events. It was going to be a mammoth task to organise this prestigious event to celebrate the 25th Anniversary of the Orchestra of St John's Smith Square but it offered an excellent opportunity to work collaboratively with the Alzheimer's Society to raise funds for both charities. As anticipated, the evening was not without its problems!

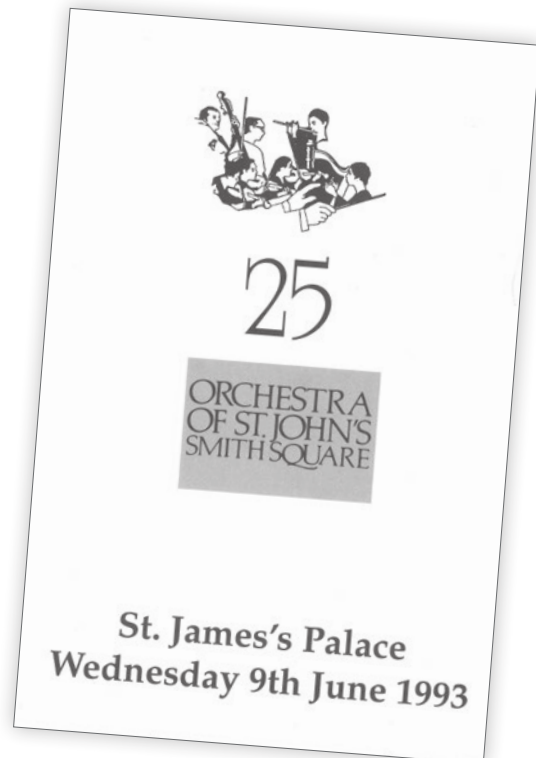
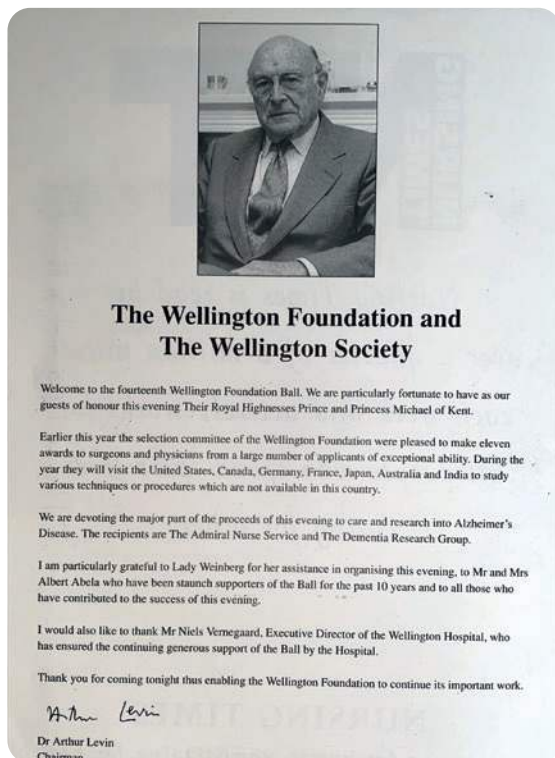
The state rooms in St James's Palace may be stunning, but they are without air conditioning to which we are now acclimatised – not ideal on the hottest recorded June evening of the year. One of the main musicians, Spanish Harpist Marisa Robles, informed us at lunchtime that she had damaged her plucking finger and was unable to perform. Marisa kindly joined us to explain this to the guests and amused the audience regaling anecdotes of previous catastrophes. Her place was taken at very short notice by the heavily pregnant wife of the leader of the orchestra who sang Scottish folk songs wearing a discreetly placed tartan shawl! This unexpected interlude was followed by the brilliant percussionist Dame Evelyn Glennie.

The two events above proved good experience for the future and I was grateful for the funds raised towards developing Admiral Nursing. It was reassuring to know we would be starting the Charity with funds in the bank!



The Event Committee for the Gala Concert at St James's Palace





Representatives of the new Charity meet HRH Princess Alexandra

Setting up office

Memories of shared offices with Shaftesbury plc, now Shaftesbury Capital

I soon realised enthusiasm alone would not carry me too far along this unknown path of starting a national charity from scratch; I accepted I would need help. In January 1994 I set to work in the tiny room kindly offered to me in the offices of Shaftesbury plc at 11 Waterloo Place, a stone's throw from Piccadilly! While awaiting the Charity's official registration there was plenty of ground work to be done. I will always be grateful to my brother Peter for this generous opportunity.

The entire Shaftesbury team made me and subsequent staff members feel extremely welcome, including us in several office events such as their incredibly indulgent Christmas lunches. In time, the company supported the Charity in many ways, attending fundraising events and sponsoring teams at the Charity's annual golf days.

"The concept of co-working offices is all the rage now, so I think we were ahead of the game"

Tom Welton – Director of Shaftesbury plc



"We all got on like a house on fire"

Elizabeth Neville – PA at Shaftesbury plc

"Sharing summer days out and Christmas parties, it was good fun having them around"

Gill Smith – PA at Shaftesbury plc

The first staff appointments



Hilary Leslie – Fundraising Co-ordinator/ Director of Fundraising and Communications

A great friend Hilary Leslie and I had worked closely together over many years fundraising for Cystic Fibrosis. We had also recently run a small informal dried flower business from my home, and whilst working on our creations had often spoken about the various options available to us in the future. We both envisaged this might be more riveting than that currently offered, gathered round the large table tennis table which doubled as an excellent work surface during term time. As our business came to a natural end, and knowing that Hilary was also keen to explore new opportunities, I wondered whether she might be willing to join me in playing a part in my new venture.

With our combined charity finance and fundraising experience, we felt we had a suitable knowledge base, and had already proved we were able to work together successfully. We took full advantage of the networking opportunities which arose. We are seen here at an event at the then fashionable Soho restaurant the Red Fort in Dean Street.

I was delighted Hilary agreed to join me as the Charity's first Fundraising Co-ordinator, though this title was later changed to Director of Fundraising and Communications as her role grew and, as Hilary explained, a superior title helped greatly in opening doors.

Hilary joined me on 17 January 1994, working part time from the tiny back office we had been allocated at Shaftesbury. We sat either side of a very large wooden desk, which took up virtually the entire space. Initially we worked at creating an image for the Charity and producing appropriate information literature to explain the work of Admiral Nurses. We had no specific allocation of funds for this, although basic start-up costs were being covered by the Foundation.

We soon realised that we would require additional administrative support. At the time we knew very little about modern equipment, having never owned a computer. Hilary once described us as "2 x A4 Pads facing each other" since everything we did was noted on large paper pads generously donated by our hosts. Letters were taken in shorthand then typed up by Beverley Taylor, PA to the Director of the Foundation Sidney Brichto.

We were very soon joined by the Charity's first official Administrator, Marilyn James. Mari, as she was affectionately known, was a very welcome addition to our small team of two!





**Marilyn James –
Charity Administrator**

Up until Marilyn's arrival on 28 March 1994, Hilary and I had relied on the support of Beverley Taylor (pictured above left, with Marilyn). Beverley was willing to assist us so much in those early days when we had no official administrative support or equipment. We came to consider Beverley as an unofficial member of the Dementia Relief team, always there to assist us when needed. It was Beverley who introduced us to her friend Marilyn, and I remain very grateful to them both for the way they took such good care of Hilary and me that first year or two.

Neither Hilary nor I completely understood Marilyn's question about software at her interview. We would have appeared very naïve, if Hilary had not reacted instinctively, responding that as a new organisation was being established we were currently considering options.

The small office next door was kindly made available to us, as there certainly was no room in ours. Having acquired the necessary computer equipment, Mari was soon able to join us.

Even then we received many calls from carers. As the first point of contact it was at times both difficult and upsetting for Mari who later attended an informative telephone counselling course which helped her to support the carers and allowed her to reduce the length of each call. Mari's direct telephone line has been described as the Charity's first Dementia Helpline.

Mari moved with us to Pegasus House, Sackville Street, where the Charity was allocated very generous offices, sharing with the Levy Foundation and Shaftesbury plc.



**Huw Meredith – Development Director/
First Chief Executive**

Huw Meredith was appointed as Development Director of the Charity, joining the growing team at the same time as Marilyn James just before the official launch of the Charity in March 1995. The initial title for Huw's role, Development Director, was agreed as the Charity was not yet deemed large enough to warrant a Chief Executive position. Huw had previously worked for various charities and had worked closely with carers at the Carers National Association (now Carers UK).

Prior to Huw's arrival I was probably occupying both the role of Chair and Chief Executive of the Charity. Later Huw's job title was changed to Chief Executive, and it was at this point that I had to relinquish my combined roles in order that the Charity could develop on a more professional footing, alongside other charities. Huw introduced the Charity to both senior nurse John Tait and Ann Windiate, who had always supported Admiral Nursing in her position as Chief Executive of Riverside Mental Health Trust in South London.

In 1996 Huw was largely responsible for the Charity's report 'The Care Must Be There' produced in partnership with Kensington, Chelsea and Westminster Health Authority and Westminster Council. It was the Dementia Relief Trust's first official publication which acknowledged the Charity's early recognition of the particular difficulties faced by families seeking age-appropriate care.





Walter Wills – Director of Research and Practice Development

I met Walter Wills with Margaret Butterworth prior to the start of the Charity. The two of them had first met during the closure of Friern Hospital. Walter had been part of the research team considering the future of the current patients, and joined the Charity as Research and Practice Development Co-ordinator in 1996. Margaret felt Walter could help guide the new Admiral Nurses to change their focus as mental health nurses from the patient to the family carer, since we were aware that this would be a very different way of working for the Nurses and that it was likely that they would require support and advice, in addition to the normal supervision for their ongoing casework.

Walter began considering the possibility of a research proposal. After further discussion with Margaret and Sidney Brichto (Director of the Joseph Levy Foundation) Walter embarked on a research study to look at how the Admiral Nurses perceived dependency and control in their relationship with family carers. This research was published by Walter with Bob Woods (now Professor Emeritus in Ageing and Dementia at Bangor University).

As we began to outgrow the offices in Sackville Street, Walter and Alison Soliman (Director of Education and Training) spent two years working from a satellite office across the road in Vigo Street. Walter left the Dementia Relief Trust in 2003 but was commissioned to continue the practice development of the Nurses for four further years. It is important to record that Walter's time and support for them during these formative years was much appreciated by the Admiral Nurses, who were sad to see him leave. His departure was also felt at the annual golf days, by those on the Charity's golf team including team member, trustee David Brettle.



Alison Soliman – Director of Education and Training

Alison Soliman joined the Charity in 1996 as Education and Training Co-ordinator, though her title changed later to Director of Education and Training. The role was created to develop the Admiral Nurses' education and training strategy, enhancing the clinical nurse specialist role. This post was funded by a generous grant of £50,000 from Marks and Spencer plc. Jane and Hilary are seen here receiving the first instalment from Assistant Manager Paul Solly at the M&S offices above their store in Oxford Street.



Alison took on the organisation of important dates in the Admiral Nurse calendar for training and practice development. Alison left in 2003, and she is very much remembered for her contribution towards the Admiral Nurse's Competency Framework which was launched that same year. Others will also recall Alison's exceptional knowledge of popular music which enabled us to finally conquer the competitive Shaftesbury Christmas Quiz team!

The Charity was gaining momentum and beginning to find its feet. At the time Alison described the Charity as *"Moving from an 'around the table' organisation to something more professional"*.

Introducing the Charity

Challenges at the start

A large majority of carers wish for care to be continued in their own home so it was crucial they learnt about the professional support Admiral Nurses could offer them. Early on, leaflets which could be placed in libraries or GP surgeries were found to be one way of spreading the word to people who would benefit – there was no social media on which to advertise or fundraise in those days.

I had some commercial business knowledge having run my own interior design partnership, and Hilary's original background in communications and advertising proved invaluable, particularly when compiling the information literature. The design for the leaflets was kept basic, using a simple blue and white colourway which kept costs to a minimum.

Creating the image



Raising the profile

Alzheimer's International Conference 1994

In the Autumn of 1994 Monica, Hilary and I travelled to attend the 10th Alzheimer's Disease International Conference at the University of Edinburgh, with the aim of introducing the Charity and encouraging relationships with other organisations. I was naively expecting everyone to be welcoming but our introduction to the unexpectedly competitive charity world was a little different from what I had imagined.

However, it proved to be a memorable visit. We were privileged to be amongst 700 delegates to witness the inauguration of the very first World Alzheimer's Day by the World Health Organisation on the morning of 21 September 1994, the day the conference opened. This has been celebrated on the same date every year since.

Reception at Institute of Directors 25 January 1995

Keen to meet with other organisations in the dementia field in order to be transparent about establishing a new charity, we held a Reception at the Institute of Directors. Our intention was to introduce the Dementia Relief Trust and to explain the aims and objectives of the Charity and the important work of Admiral Nurses, together with our aspirations for the development of the Service. It was felt it would be an opportunity to offer an introduction to the Charity and develop relationships with others in the same line of work to avoid duplication.

"It just seemed to me such a shame we couldn't make a more common cause for all the people who were involved in dementia care in one way or another because we were all complementary"

Ann Windiate



It wasn't difficult to understand that with limited funding available in this unpopular arena, others might soon feel uncomfortable about our existence. Although the Charity was well received, at the time I very quickly became aware of the threat any new charity might bring if successful. As the number of charities working in dementia grew I accepted that other organisations might not easily welcome newcomers.

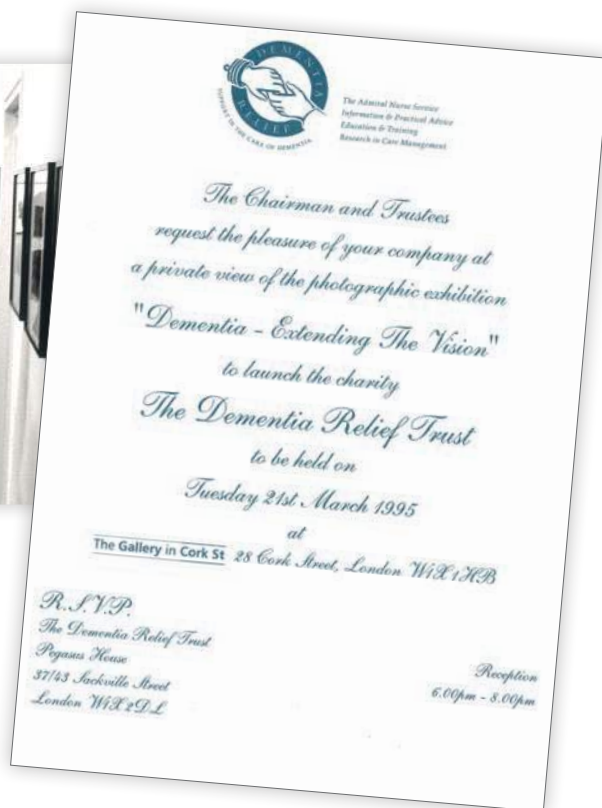
When Hilda Hayo, Dementia UK's current CEO and Chief Admiral Nurse, joined the charity sector she too described her surprise at the unexpected lack of co-operation and competitiveness: *"I expected charities to all be working nicely together and being supportive of each other. One of the aims I had was to get charities to work together"*.

As the Charity has grown I feel respect for Dementia UK has increased. I understand there has been much improvement and the dementia charities are working collaboratively as "One Dementia Voice". Hopefully this is a sign of improved communication between all those working towards a better life for those affected by dementia.

Official Launch of the Dementia Relief Trust

A photographic exhibition 'Dementia – Extending the Vision' at 'The Gallery', 28 Cork Street, London – Tuesday 21 March 1995





Hilary and I focussed much of our attention on planning the official launch for the Charity. The idea was to create an event which would place the Charity firmly on the map, raising awareness of both the work of the Charity and dementia, in addition to the much needed funds no charity can function without.

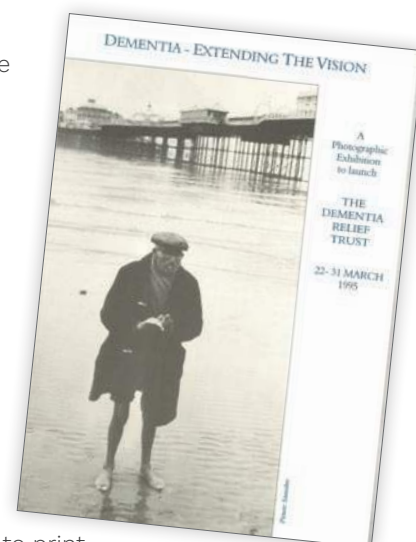
Most of the credit for the various 'Launch' events must go to Hilary who truly put her heart and soul into her innovative idea to produce a photographic exhibition focussing on the lives of families affected by dementia. Once agreed by the trustees, Hilary identified 'The Gallery in Cork Street' which was geographically suitable and available for hire on a weekly basis. Once dates were agreed and a contract signed – we were on our way! We hired the Gallery for ten days from Monday 20 March to Saturday 1 April 1995. Various private views were offered throughout the fortnight to other organisations such as Alzheimer's Society, Carers National Association and Margaret Butterworth's CRAC Dementia, allowing them to learn more about our ideas for the future, whilst once again offering us the opportunity to network. It was also open to the general public at other times.

Hilary worked tirelessly throughout to create a thought-provoking exhibition. The photographs were gathered from a number of sources: professional photographers on assignment, family carers and from specially commissioned student work. The images combined to capture with dignity the human story of people with dementia and those who cared for them. The exhibition included photographs of those who had played an important part in society and who had not been spared the disablement of this condition, the theme being that dementia ignores individuals' past strengths and respects neither wealth nor privilege. The images produced showed the real world of the person with dementia in which, sadly, memories can be snatched away for ever.

A friend of Hilary's, Sue Cohen, who became a loyal supporter of the Charity, helped by researching an image she had seen featured in an article in one of the Sunday colour supplements. It transpired that the photograph had been taken in 1966 by Lord Snowdon. The description, as quoted in the invitation brochure, reads: *"Each morning Mr Phillips 66 years old leaves his room at a Brighton boarding house and walks to exactly the same spot just east of the Palace Pier. He rolls up his trousers and moves a few yards into the water. He has been known to stand motionless*

from 5.30am till 11 at night." His landlady says: *"He just went a bit senile."*

Hilary was extremely fortunate to eventually communicate personally with Lord Snowdon who, without hesitation, gave his permission for the photograph's inclusion in the launch exhibition and use on all promotional literature. In addition, he very kindly offered to print a copy for the Charity at his studio.



The official launch of the Charity was a Private View of the photographic exhibition 'Dementia – Extending the Vision' on the evening of Tuesday 21 March 1995. A Press Preview was scheduled for 11am the same day. My own family supported me at the Private View; it meant a lot to have them all there.

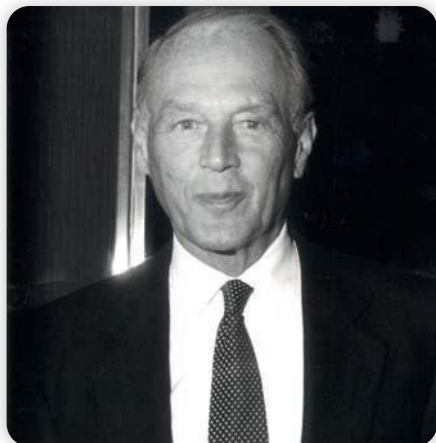
I was becoming accustomed to speaking openly about my father and his illness, and realised how a relative's honest account hits home. After the launch I was very surprised to receive a substantial donation from someone I didn't know but whose father also had vascular dementia. He told me he had been very touched by my true and open account of my father's illness.

Recently appointed Patron of the Charity Richard Blanchflower attended the morning Press Preview with his sister Stacey Cowling and her husband. We were most grateful to them for agreeing to donate an image of their late father Danny Blanchflower, the famous Tottenham and England footballer who had only recently succumbed to Alzheimer's disease at an early age. They were accompanied by two of Danny's friends, famous contemporaries from his playing days, Tottenham and England player/manager Bill Nicholson and another Tottenham team mate Tommy Harmer.

The potential risks of frequent heading of the ball are now beginning to emerge and be recognised. Hilary and I recall discussing this very issue at the Launch with these retired players.



The following day we received the Charity's first coverage in the national press, reporting that Sir Michael Richardson, an investment banker, a recently appointed Patron of the Charity, had attended the Launch Private View. The following year he became a trustee of the Charity.



I had been introduced to Sir Michael, then Chairman of investment bank Merrill Lynch, by a friend the late Michael Marks, who was at that time Chief Executive of the firm. Since Sir Michael's wife Paddy had been diagnosed with young onset dementia he appreciated and completely understood the work of Admiral Nurses. This meeting led to a long and successful relationship with the Richardson family. Victoria (Vicky) Wilson, Michael's eldest daughter, and her husband Anthony, who sadly died in 2018, particularly had a long association with the Charity in many different ways.

Even the younger generation of the Wilson family became involved. Following in her mother's footsteps, Vicky's daughter, Octavia (Posey) Wilson, raised over £500 for the Charity at her school, St Andrew's in Eastbourne. Octavia had been inspired by her grandmother Paddy.

I will always remain grateful to the Richardson family for their valuable support of the Charity at a time when it was most needed. Their loyalty never wavered. Above all, it was refreshing to meet another family who not only fully understood our objective but were willing to speak openly about their own personal experiences, which at the time helped so much to increase other people's understanding of dementia.



Victoria Wilson (Vicky) Chair 2005–2009



Apart from her interest and work in promoting the development of the Admiral Nurse Service, Vicky worked on several early key fundraising events, namely 'Fashion in Mind' and 'The October Club Racing Dinner' with her father and younger sister Melissa. Vicky also introduced Penny Sheehan who organised a series of very popular tennis tournaments at the Vanderbilt Racquet Club, which helped raise both vital funds and the profile of the Charity. Vicky chaired the Carol Concert committee prior to joining the Board of Trustees when her father retired, later becoming Chair.



The photographic exhibition extends the vision to the House of Commons, 6–10 November 1995

The exhibition 'Dementia – Extending the Vision' which launched the Charity moved briefly the same year to a more exalted venue, the Upper Waiting Hall at the House of Commons. The Charity was supported by Clare Short MP who very kindly acted as our sponsor and officially opened the exhibition. Although not open to the public it was hoped this would be an opportunity to bring the work of the Charity to the attention of MPs to gain their support.

The exhibition was officially opened on 7 November by Clare Short, who gave a moving account of her own experiences as primary carer to her husband Alex Lyon MP who died in 1993. Clare had most generously allowed a photograph of her husband to be hung in the launch exhibition and agreed for it to be included once more.

The viewing was followed by a small tea time reception in the Jubilee Room, also attended by a number of our medical and celebrity Patrons. It was a welcome opportunity to bring the Charity's work to another audience. It had been envisaged that we might take the exhibition to other venues around the country; however for various reasons this never materialised.



The October Club

Later that same year 1998 we once again had cause to be indebted to the Richardson family, when Vicky introduced the Charity to David McDonough, the Chairman of The October Club, a group formed by people working in the City which raises substantial sums to make a difference to a young charity. A Dinner, complete with a racing programme and an auction, takes place one evening every October. This annual event still continues today.

We were fortunate to fit the Club's criterion perfectly as a small but growing charity with projects of a transformational nature covering several regions across the UK. We could also guarantee the use of the funds within three years.

This opportunity was so important, I felt it necessary to fly back from holiday for the evening to attend the Charity's interview. Fortunately, it proved to be a journey well worth the effort when the following morning I learnt our bid had been successful.

The October Club Ascot Race Day – 24 July 1998

We were the first charity to benefit from a new addition to their calendar 'The October Club Race Day' which took place on a pleasant summer day in July. In return for acting as Ambassadors for the day, Hilary and I joined 100 guests for a delicious lunch in one of the private dining rooms whilst my daughter had a different yet equally enjoyable experience with friends fundraising by noisily shaking buckets round Ascot Race Course.

We watched the appropriately named 'October Club Admiral Nurses Charity Handicap Stakes' from the stands where we were excited to view banners displayed around the course advertising the race. This had to be the first time the 'Admiral Nurse' name received national exposure on BBC television.

The photos taken then are not up to the standard of the present day but we didn't have mobile phones complete with powerful cameras so could not easily capture every event as it happened. A Kodak Instamatic, small enough to fit into one's bag, had to suffice.



The October Club Racing Dinner – 14 October 1998

The Club's 11th annual fundraising event was held one evening, needless to say in October, at the Savoy. Our new Patron Richard Wilson had the unenviable task of maintaining control of a room of 400 enthusiastic city business men. Cleverly employing his talent for comedy, he held their attention to introduce our eminent speaker, Professor Brice Pitt, Professor of Old Age Psychiatry at St Mary's Hospital London. Professor Pitt sadly died in 2021. Sir Michael Richardson's younger daughter Melissa spoke movingly about her family's experience of dementia.

The evening raised a staggering £265,000 for the Dementia Relief Trust, giving the Charity the opportunity to extend the Admiral Nurse Service into the north west of England. We were hugely appreciative of the outcome, the amount raised and the interest generated in the Charity. Could this be an indication that a clearer understanding of the effects of dementia on families was emerging?

Bearing in mind how long ago these events took place some substantial sums were raised. Although there were times when we lived a hand-to-mouth existence, the larger sums raised

allowed the Charity to expand the Admiral Nurse Service out of London. The Charity's annual income can hardly be compared to that raised in so many different ways today, but it should be remembered the Charity was also still struggling to explain the Admiral Nurse's innovative role to support the family carer.



Richard Wilson OBE – Patron

Well known Scottish actor, theatre director and broadcaster Richard Wilson is most famous for the role of Victor Meldrew in the popular television series 'One Foot in the Grave'. Richard was introduced to the Charity in 1997 by Dr Monica Greenwood when he agreed to present certificates at a Training Award Ceremony. He commented later: *"These events offered an opportunity to meet the carers and specialist Admiral Nurses whose work I continue to admire."* Richard was welcomed as an early Patron of the Charity in 1998. A favourite with the Nurses, he supported several early fundraising events.



Working with the Charity's Patrons

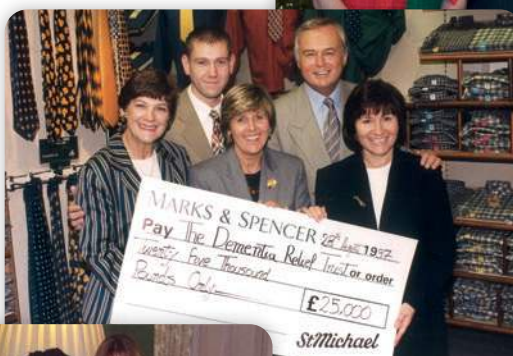
It is widely recognised that to have the endorsement of a charity's work by a public figure can make a positive difference. We worked hard to secure the support of several celebrities who helped raise our status in the increasingly competitive charity world.

Patrons represented the Charity in a variety of ways; speaking at prestigious fundraising events or anniversary milestones; reading at Carol Concerts; opening a charity Bazaar or accepting a cheque on behalf of the Charity. I was particularly grateful to those Patrons and trustees who were willing to give their evenings to present certificates to the eager students at the Awards Ceremonies. Several understood very well the complexities of providing care for a person with dementia; and realised how their willingness to share their personal experiences would make a difference.

I acknowledge here how much the Charity and I owe to all those who generously give their time to support the Charity particularly those who retained their faith in us throughout the Charity's formative years.

"If you can get high-profile people, that makes an impact"

Peter Carter



Admiral Nurses in an Ambassadorial role

Admiral Nurses often attended fundraising events, acting as Ambassadors to promote their role. I have heard some amusing accounts of how, having worked till late, they scrambled to reach venues on time having had to change from work clothes on the Tube. In spite of this they somehow always managed to arrive looking perfect. They have been described as a feisty bunch and I soon realised Admiral Nurses are past masters at burning the candle at both ends; but I was so very grateful for their willingness to give up their valuable free time in support of the Charity.



Mayor Of Brent – Mayoralty – Rose Ball 8 April 2000

Similarly to London Transport buses, you don't see a London borough Mayor for some time then two or more come along at once! The Dementia Relief Trust was one of the charities chosen by the Mayor of Brent, John Labor, to benefit during his year in office from 1999–2000. The main event was the annual Rose Ball.

Newly appointed Admiral Nurse Susan Drayton didn't know quite what she'd taken on when she attended the Ball during her very first week in post. She is photographed here with myself, Admiral Nurse Dave Bell, the Mayor of Brent and the newly elected Mayor of London Ken Livingstone. I explained there was more to Admiral Nursing than meets the eye!

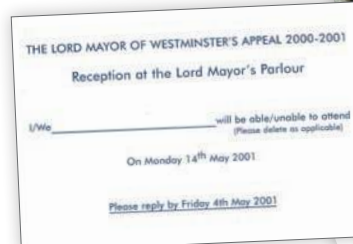
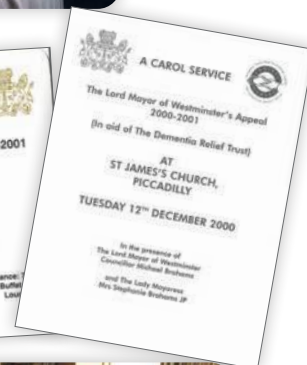


Lord Mayor Of Westminster – Mayoralty – Cllr Michael Brahams – May 2000-2001

This was an exceptional opportunity to promote awareness of Admiral Nursing in central London and to raise the necessary funds to expand the number of Admiral Nurses.

A close family friend, Michael Brahams, had been appointed Lord Mayor of Westminster for the Millennium Year 2000–2001, but even more exciting was the fact he had nominated the Dementia Relief Trust as the charity beneficiary for his year in office.

Though Michael and his wife Stephanie, who joined us on the newly formed Westminster Appeal Committee, were incredibly occupied with official duties they still often found time to support the Charity. As the Charity's Appeal Ambassadors, they helped us achieve our aim to raise the necessary funds to establish a new Nurse Consultant post in partnership with Brent, Kensington, Chelsea and Westminster Mental Health NHS Trust to heighten the profile of carers' needs and enhance existing Admiral Nurse provision. It had been encouraging to learn from Stephanie how well received the Charity had been when Michael had originally announced his choice.



The Launch of the Lord Mayor's Appeal Year in May 2000

A fundraising committee was formed for the Charity's Appeal Year which launched in the Lord Mayor's Parlour, situated on the 18th floor at the top of Westminster City Hall. It is the perfect space in which to hold functions with exceptional views over Hyde Park and Buckingham Palace. We were very grateful to have the use of the Parlour for various functions throughout the year and to benefit from the consistent support of Kevin Taylor, then the Lord Mayor's Private Secretary, and his team at the Westminster office throughout this prestigious year.

Several fundraising lunches were held in the Mayor's parlour including one hosted by Michael's Deputy Lord Mayor Catherine Longworth who very kindly hosted an event for her friends, then generously donated the proceeds to the Charity.

A Private Dinner

As part of this celebration year A Gala Dinner was held on 7 November 2000 at the beautiful Hampstead home of Michele and Clive Warshaw who generously sponsored the event, allowing all proceeds to go directly to benefit the Charity. Later Michele and Clive very kindly agreed to host another equally enjoyable Dinner on 18 May 2005 to celebrate the Charity's 10th Anniversary Year.

A Tutored Wine Tasting

A tutored wine tasting was also organised in the Parlour by Lionel Frumkin whose wife Gillian, a great friend, sat on the Appeal Committee. The many wine buffs present were most amused when the quiz prepared by Wine Correspondent Andrew Henderson was won by a table of our combined children, the youngest guests in the room!

Dinner and Auction in the Long Room at Lords

Although normally for the exclusive use of MCC members, Lionel Frumkin somehow gained permission from the then Secretary Roger Knight to hold a prestigious dinner for the Charity in the famous Long Room at Lords Cricket Ground. Sports and cricket commentator Christopher Martin Jenkins agreed to give the 'After Dinner' speech. Unusually for an event of this kind at Lords, ladies were permitted to attend.

The Charity's first Carol Service was held on 12 December 2000 at St James's Church Piccadilly, in the presence of Charity Ambassadors the Lord Mayor of Westminster and the Lady Mayoress. This event has been held annually since, apart from 2004 when it was replaced by a Christmas Appeal and 2020 when public events were cancelled due to restrictions imposed by the Covid 19 pandemic.

All credit for the original event must go to the late Alison Pimlott and Victoria Wilson supported by an extended Event Committee. The following year an independent Carol Service committee was formed, originally chaired by Alison who took responsibility for establishing this as a regular event in the Charity's calendar. In 2006 the event moved to a new venue, St George's Hanover Square, where substantial sums are now raised annually.

My outstanding memory from that evening is walking down Piccadilly like a robber armed with two immensely heavy carrier bags containing the evening's church collection. I had offered to take it with me for safekeeping. I made a mental note to ensure more secure arrangements were in place the following year!

New Year's Day Parade – 1 January 2001

Some extremely hardy, loyal friends and Admiral Nurses joined together and walked as a group following the Lord Mayor of Westminster's Parade, shaking buckets for the crowd to donate to the Charity. It would be an imposition at any time but to request their presence by 8am on a grey New Year's morning was certainly above and beyond the call of duty! The Frumkin family, Stuart and Kathryn Sanders, Judith Navey, Admiral Nurses Penny Hibberd and Debbie Hawkins and families all warrant a special mention for their commitment.

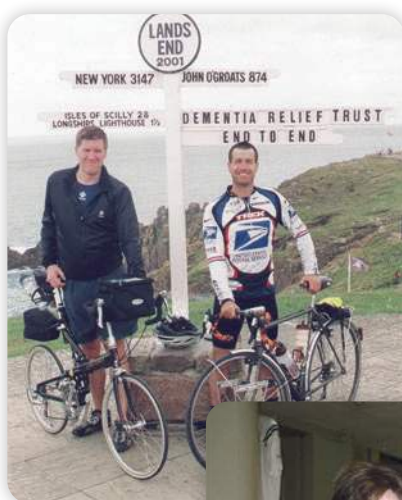
Gala Concert

The year culminated in a Gala Concert held at the Goldsmiths' Hall on 1 March 2001. The concert in this splendid setting, introduced by TV and radio presenter the late Richard Baker OBE, featured three outstanding young musicians who formed the Kempf Trio. The Charity was most grateful to Carmel Hart of Carmel Arts for her help in the organisation of this event.

At the end of the year a cheque for £125,650 was presented at a final Reception in the Mayor's Parlour. After all the hard work we were delighted to hear that we had raised the highest amount for any charity during the Mayoral Year, a record which stood until very recently.

Fundraising keeps the Charity afloat

It wasn't easy to encourage interest in our very small unknown charity. Events were an invaluable way of raising unrestricted funds and finding new support. People faced personal goals, training for sponsored walks, swims, cycle rides and even marathons when the Charity could secure places. We also introduced Comedy Evenings, Tennis Tournaments and Golf Days. We didn't have the infrastructure to set up anything too ambitious, so progress was slower than we might have wished.



The Charity also benefitted from being nominated by Golf Club Captains during their year in office. A particularly innovative Lady Captain, Val Gofton-Salmond from Sandford Springs Golf Club in Hampshire, during 2003/2004 encouraged members to compile and sell an easy cook book for those who would rather have a nine iron in their hand than an egg whisk! Sue Rudolf (pictured here) at my own club at the time Finchley GC kindly nominated the Charity during her term in 2012/2013. I'm pictured here with my winning team at Hadley Wood GC.

Tea Parties and Barbecues were hosted by friends and their families, though we gradually began to reach out to other groups in the community. The general public were finally realising that, with a rapidly ageing population, dementia was going to become an area of increasing concern. Admiral Nursing was beginning to make its mark as people who had been helped spoke up. Respect for the Charity was growing.



Small events were organised within local Admiral Nurse teams. One of the Admiral Nurses, Raminder Sarna from the Harrow Service, even travelled all the way to Iceland for a sponsored walk raising a well-earned £5,000. Another, Consultant Admiral Nurse Karen Harrison Denning, bravely shaved her head to raise yet more funds for the Charity! It seemed people would try anything and everything. Everyone, even the Nurses, joined in enthusiastically to support the small fundraising team to keep the Charity afloat!



Pam St Clement with Emily & Debbie (award winner)

The Nurses often worked overtime volunteering to help at events such as acting as ushers at the Carol Concert. In 2002 award winning Admiral Nurse Debbie Hawkins was invited to read a lesson, not realising the event would coincide with her young daughter's birthday. Emily was initially very upset, till as an avid EastEnders fan she was introduced to, then photographed with, Pam St Clement, who played Pat Butcher in the popular TV series. It made Emily's day! Pam's amusing rendering of 'The Twelve Days of Christmas' by John Julius Norwich was enjoyed by the rest of the congregation and Emily had a wonderful story to impress her friends the following day!



Sponsored Cycle Ride 2001

In 2001 Andy Stephens, brother of the Charity's Chief Executive, cycled from Land's End to John O'Groats with his friend Graham Glen, raising both funds and awareness along the way. I met up with them in Bolton after they had been photographed on the set of Coronation Street with the Manchester Admiral Nurse team and Actor Sally Lindsay from the popular TV series.

Tennis Tournaments 1999–2002

A series of successful tennis tournaments was organised by Penny Sheehan with the grateful support of Charles and the late Susanna Swallow, owners of the famous Vanderbilt Racquet Club. The tournaments were very well attended, great fun and once again helped increase awareness of the Charity.



Nominated Charity of the Year – West London Synagogue

Thanks to the support of synagogue members Ruth Jacobs and Hermie Jankel, with their committee, the Charity was fortunate to twice be chosen as one of the nominated charities to benefit from fundraising activities and donations throughout the year. Patron Martyn Lewis very kindly came one Sunday to open an Autumn Bazaar.

Wembley End of an Era

The Charity was delighted to be one of those chosen to benefit from Wembley National Stadium's 'End of an Era' campaign. Young staff members, friends and family were thrilled to have the opportunity to play on Wembley's sacred turf!

Fore! dementia Golf Days from 2002

We held several successful and enjoyable Golf Days. The first was generously organised by my son-in-law Daniel Ellison at West Hill Golf Club in Surrey. In spite of the inclement weather the day proved successful. Later Golf Days were held at Porters Park, Hadley Wood and Brompton Hall. This was the one time the 'Fore! dementia' branding worked well!



Staff, Trustees, friends and family support the Charity

Private Screening 'Iris' – Screen on the Hill 22 January 2002

Very occasionally there are times when everything falls neatly into place. The Charity's introduction to actor Jim Broadbent was one such occasion.

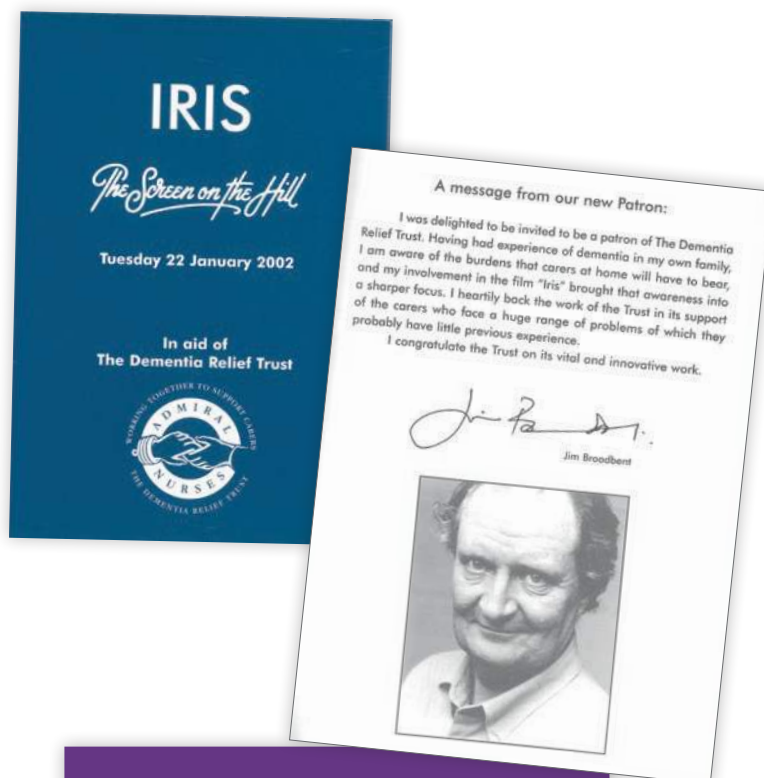
In the autumn of 2001 the newly formed fundraising committee began considering the appointment of new Patrons to increase awareness of the Charity. Ann Gordon, a relatively new committee member, suggested she ask Jim, who she felt would be sympathetic to our cause, since he had cared for his mother with Alzheimer's disease till she passed away in 1995. At the time this proposal prompted little reaction. Embarrassingly, though Jim was already a successful actor, few on the committee recognised his name.

Ann then explained there was family connection and caught the committee's attention by revealing that Jim was to play a leading role in the film 'Iris', the sad story of novelist Iris Murdoch's decline into dementia. He was to play her husband John Bayley, opposite Dame Judi Dench in the title role.

After this revelation Jim's relationship with the Charity seemed predestined. He even lived close by in Hampstead, a stone's throw from the Charity's Camden offices. When contacted he was delighted to help.

The Charity organised a Private Screening of 'Iris' at Hampstead's 'Screen on the Hill' cinema on 22 January 2002 just a few days after the film's release. As a local resident and our newly appointed Patron, Jim agreed to introduce the film though unaware at the time of his forthcoming nomination for a Golden Globe award. He arrived that evening direct from Beverly Hills, California with the winning statuette for Best Actor in a Supporting Role.

A few months later Jim was to be incredibly successful yet again, winning a coveted Oscar in the same category. He continues to support the Charity whenever his busy schedule permits.



Jim Broadbent – Patron

Jim Broadbent came to prominence as a character actor for his many roles in film and on television. Jim became an early Patron in 2002 and has attended several events since in support of the Charity including readings at Carol Concerts. On 26 August 2012 he delivered the Radio 4 Appeal raising an incredible £28,000 for the Charity and in 2017 he presented the BBC Lifeline Appeal raising over £18,000 on behalf of Dementia UK. Jim continues to support the Charity in Dementia UK's 'Ambassador' role. Jim recalls when first introduced to the Charity: *"From my own experience I was all too aware of the strain on carers and it was wonderful to learn of a charity reaching out to those carers in such a direct and positive way."*

"Over the years it has been mightily impressive to see how Dementia UK, as it now is, has gone from strength to strength, giving more comfort, advice and practical support to so many people. I offer my heartfelt appreciation and congratulations for all the magnificent work"

Jim Broadbent

Chairman's Angels Lunches

I always said I would try anything once; however in order for this idea to succeed, individual donor support was required. I relied heavily on a handful of generous friends and their introductions. The idea was to hold a series of small private lunches with an engaging speaker to encourage investment in the Charity in the way theatre angels support new productions. Our first trial was beset with problems from the outset, when our guest speaker failed to arrive leaving me to address the guests. They were very understanding and equally generous, so a substantial amount was raised. Fortunately, there were no hard feelings. It transpired both parties, the Charity and the guest speaker, were similarly to blame. Good hearted Patron Katie Derham recalls: *"We laughed – what else could we do?"*

"I have been so pleased and proud to see the Charity go from strength to strength"

Katie Derham

Katie Derham



I met newscaster and TV presenter Katie Derham in a rather roundabout way. Trustee Vicky Wilson's daughter Camilla had worked with Katie's sister, and their mother had died from Alzheimer's disease in 2003 at the very young age of 61. Katie agreed to meet and was only too willing to help, immediately recognising the benefit of Admiral Nurses. Katie first presented certificates at Award Ceremonies and attended many other events, often speaking movingly about her family's experience of dementia. Katie became a much valued and active longstanding Patron of the Charity.



"How could I help? Well Jane you were of course extremely persuasive! I tried to do what I could, and was acutely aware that you and your then small team were extremely stretched"

Katie Derham



Growing the Charity, expanding Admiral Nursing

As the first Chief Executive of the Charity, Huw Meredith led the early development work at the time when Admiral Nursing was still in its infancy. His key task was to create a structure to support the model and enable Admiral Nursing to grow.

Although the original Admiral Nurse Project ended in March 1993, the Joseph Levy Foundation agreed to an additional year's funding for those Admiral Nurses to allow the health authority time to put in place funding for the future. Mark Lawton left at the end of the Project and was replaced by Robert Moroney and later Alison Coignard took over from Ann Medina. These two nurses continued to work as Admiral Nurses under the auspices of Parkside Health Authority, based at Latimer House. These Admiral Nurses were described in an article for the North West London Mental Health NHS Trust which describes their role as *"doing an admiral job"*.

These were small beginnings: Admiral Nurses were developing their practice and defining the model in partnership with secondary mental health services in a small number of NHS trusts and with additional support from the Charity (then called Dementia Relief Trust).

"We were given the best environment to let ourselves grow, try things out and it always felt safe so that's probably where a lot of the innovations come from"

Jules Knight



NWL

Doing an admiral job

From April people in Brent caring for friends or relatives with dementia will soon be able to rely on a little extra help.

Carers are usually unpaid and often under a great strain so emotional and practical support is, therefore, very important.



**Admiral nurses
Alison Coignard
and Robert
Moroney**

To help, the Trust has managed to secure the services of two more Admiral Nurses who will be paid for by the Dementia Relief Trust which is a registered charity. These two appointments, from April 1995, will bring the number of Admiral Nurses working within the Trust's area to four.

Alison Coignard and Robert Moroney are already established Admiral Nurses working in north east Westminster from their present base in Blenheim Terrace.

Although Alison and Robert are now both funded by NWL they maintain links with the Dementia Relief Trust and also work closely with other disciplines including mental health colleagues and social services.

Alison explained their role: "Our job is to support people caring for dementia sufferers. Carers are usually unpaid – a wife, husband, son or daughter, or perhaps a friend or neighbour.

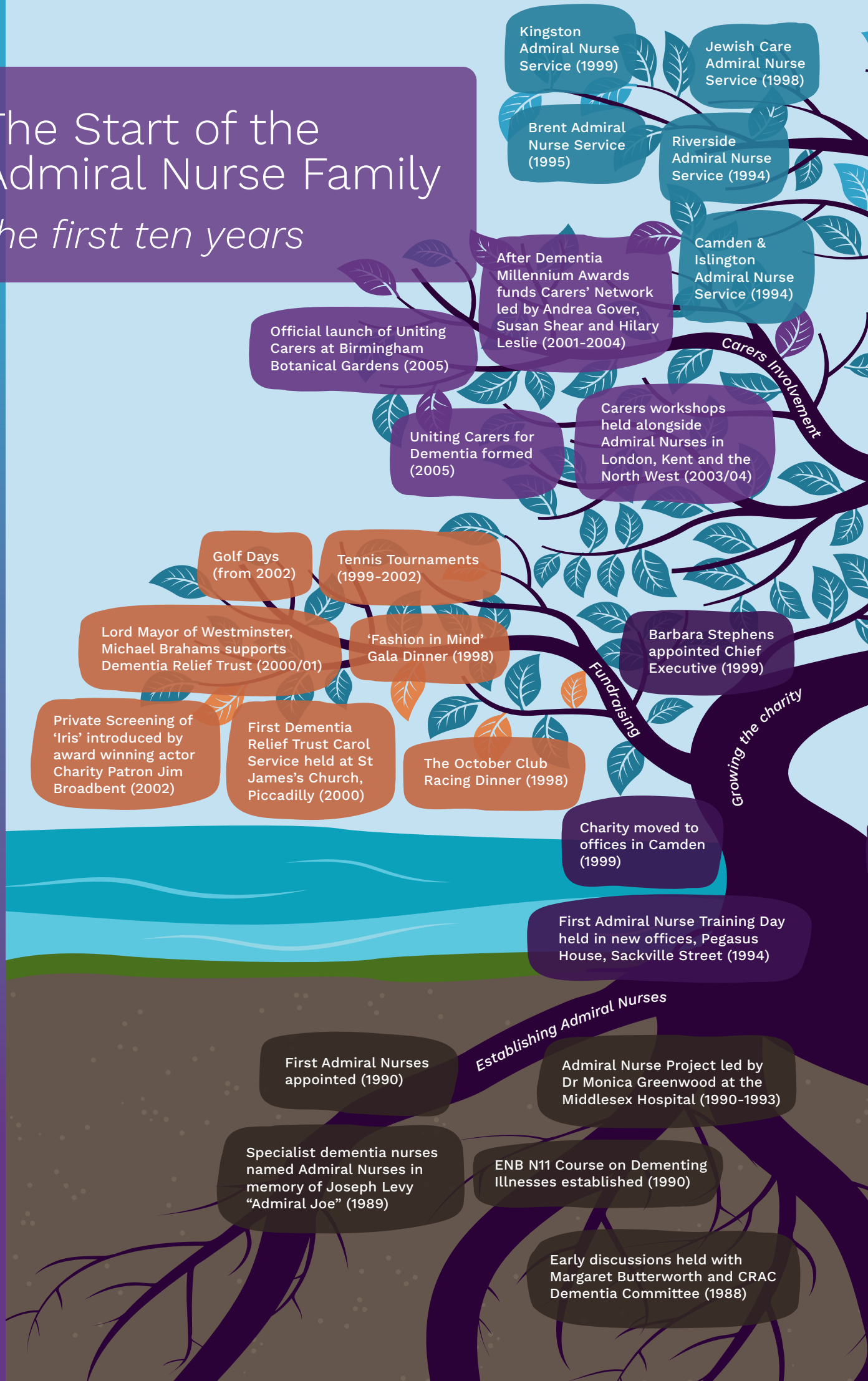
"It's important for us to give emotional and practical help. We advise on available benefits and on dealing with difficult aspects of the illness which might include forgetfulness, wandering or aggression.

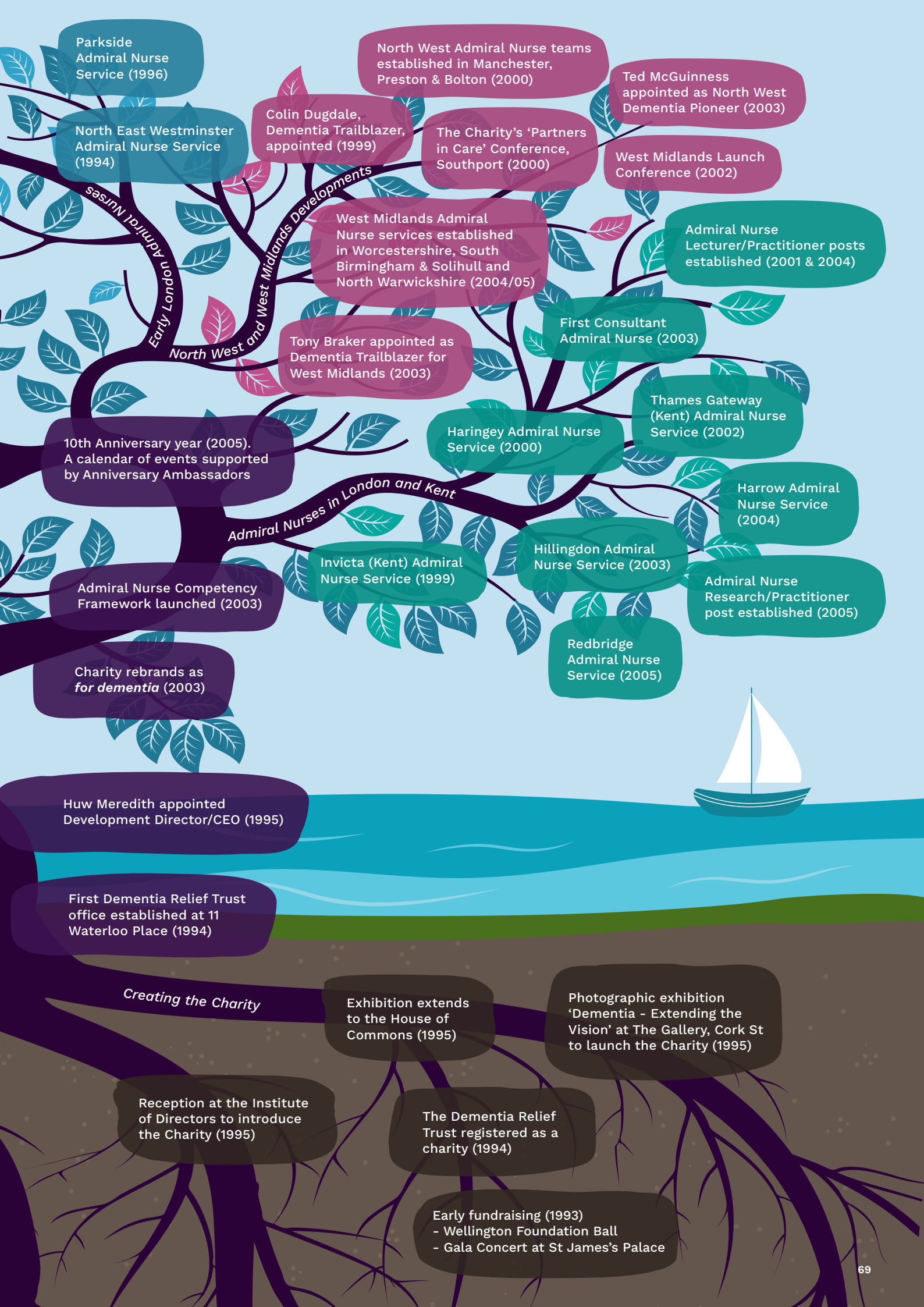
"We provide information about the dementias – Alzheimers Disease is the most common – and we hold quite a large stock of literature.

"We also help the carer to explore the different kinds of help available so that they can make an informed decision about the types of care they want. We can then refer the carers to the appropriate agency."

The Start of the Admiral Nurse Family

the first ten years





Admiral Nurse Service Launches and Anniversary Milestones

New Admiral Nurse Services were often celebrated with a launch event. Although maybe a little unusual, I always liked to attend whenever possible, believing it to be a unique opportunity to meet new, enthusiastic Admiral Nurses and identify with other family carers. It seemed important to keep in touch especially as the Charity developed. It was both touching and humbling to hear from carers how much the support meant to them. Later when forming the Carers' Network these events provided an excellent opportunity to recruit new members.

Launches often took place a few months after the Service had officially opened for referrals. Family carers and local dignitaries were often invited. I attended many over several years but remember fondly some of the early events when the Nurses, several now retired, seemed so young and a little nervous particularly if they were to speak in public for the first time.



The first Admiral Nurse Service Launch for the Parkside Team in 1996

The first official Admiral Nurse Launch, for North Kensington and Paddington, was organised in conjunction with Parkside Health Authority and took place on Wednesday 16 October 1996 at Paddington Community Hospital in the presence of the Deputy Mayor of the Royal Borough of Kensington and Chelsea Cllr Mrs Ian Frazer. The two newly appointed Admiral Nurses, Lynda McNab and Team Leader Debbie Hawkins, who had already received 45 referrals since setting up office, spoke about the support they were able to offer family carers. It was a very special day!

The Admiral Nurse Team in Manchester was established in September 2000, and its official launch was held at Wythenshawe Hall in July 2001 with Susan Ashcroft Simpson as team leader, Loraine Butterworth and Francesca Smith, who was replaced by Pam Kehoe in 2002. Susan Hazlehurst joined them later. Manchester was the only team at the time to have a Team Administrator. Nine nurses in three teams were originally planned but in the end three Admiral Nurses had to cover the entire Manchester area.

Invicta (Kent) Launch



Worcestershire Service 10th Anniversary



Preston Launch



East Kent Launch





Admiral Nurse Service Launch for Haringey in 2001

This Service opened for referrals in 2000. Their official launch was held some months later on 5 April 2001, attended by Haringey Admiral Nurse team leader Jules Knight (Jones).

I remember it clearly for two very different reasons; firstly, as it was held at the Tottenham Hotspur football ground at White Hart Lane. The Spurs team are arch rivals of the Levy family's cherished team Arsenal. I remember mentioning that I doubted my father would have approved.

Secondly the drama of the cake. It was becoming a tradition to have an iced cake complete with the Charity's logo. When their original plan failed Jules had to revert to Plan B. A quick trip to a local store to purchase an iced wedding cake tier solved the problem. A paper cut out of the Charity's logo was placed on the top then more icing added. A very clever substitution. Apparently, I was the only other person who knew as it was my job to cut the cake!



The Launch of the Admiral Nurse team in Worcestershire took place on 19 November 2004 and was attended by several carers and those they cared for, health and social care professionals, local dignitaries and the MP for mid-Worcestershire Peter Luff. Speakers included **for dementia** CEO Barbara Stephens, carer Cheryl Hudson and newly appointed Admiral Nurses, team leader Helen Springthorpe and Bob Graham.

Other special celebrations were also held to mark specific milestones, and it was a real privilege to be invited to these to see how the services had developed and expanded.



Medway (Kent) Service 10th Anniversary



6 Camden High Street



1. for dementia training unit

Further developments in the new Millennium

As a small group at the beginning, it was not difficult to bring the Nurses together. Admiral Nurse Forums started as Training Days, which were initially intended as an opportunity for the Nurses to learn more about dementia and anything relevant to their nursing role. These became Development Days, then Forums spread over more than one day offering the Nurses a chance to meet and share new ideas to continue to develop the Admiral Nurse model.

The very first Training Day was held in the Shaftesbury company boardroom on 20 October 1994, attended by 22 people including 7 of the current Admiral Nurses, together with their managers and others connected in some way with the Service. The involvement of managers and others connected with the Service was encouraged in order that the nurse's role was better understood. Guest speaker Consultant Psychiatrist Sarah Egger spoke about the production of the new drug Tacrine. Sarah was very supportive of the Nurses' work. Having

indicated she would be willing to become more involved with the Charity, not long after she became one of our first medical Patrons.

In 1999 Dementia Relief Trust moved to dedicated premises at 6 Camden High Street, next door to the original Camden Palais building (re-named KOKO). The office accommodation included a state-of-the-art (for its time) training room where the Charity could hold team leader meetings and the renamed Admiral Nurse Development Days, not to mention various emotional leaving/retirement parties and raucous Christmas parties – we certainly made full use of the facilities available! Based on the theory 'all work and no play makes Jack a dull boy' these moments offered opportunities to relieve the pressure of work, enhance productivity and build healthy working relationships. As the number of Nurses grew, other locations had to be found for some of these larger gatherings, paving the way for the expanded annual Admiral Nurse Forums. For a time, though, the offices became a welcome base for the Nurses and others closely associated with the Charity.

Bill Bennette

Bill Bennette, a successful interior designer, was eager to support the Charity after his mother received a diagnosis of Alzheimer's in South Africa. Bill first quietly organised and sponsored the Christmas trees which decorated the church at the annual Carol Concert, which he always attended with his small design team as part of their pre-Christmas celebration. When the Charity moved to its own premises, he offered his professional services freely to design and transform the three floors of the building. He also enabled the Charity to purchase all fittings and furniture at net trade and wholesale prices. I was extremely grateful for his expertise and continued generosity. Now retired to the countryside in peaceful Dorset, Bill remains a loyal supporter of Dementia UK.





The changing face of Forums

Admiral Nurse Forums now take place on Zoom which saves both travel time and expense to the Charity. The number of Nurses is much larger now so, as always, success breeds the necessity for change. I fully understand the steps taken but I remember well how much the Nurses welcomed the opportunity to meet and catch up in person with colleagues from around the country.



"We don't see each other in person very often. However, when we do it's magical, impressive and inspirational"

Victoria Lyons

Forums were also a chance to have fun. At one event in October 2008 at the Queen Hotel in Chester, members of the newly formed Practice Development team showed off their hidden talent with a rendition of S Club 7's hit 'Reach' encouraging Admiral Nurses to reach for the stars!

Journal of Dementia Care and the UK Dementia Congress

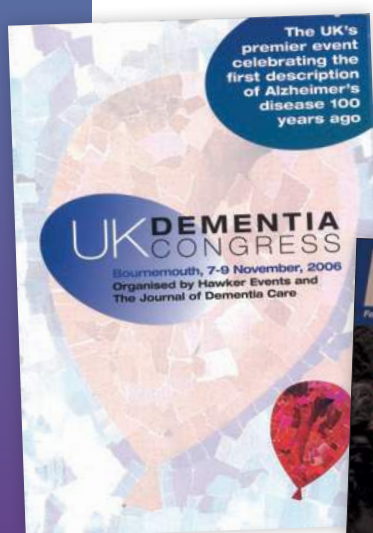
For similar reasons many of us enjoyed the annual UK Dementia Congress, arranged by Hawker Events and the Journal of Dementia Care, which proved to be a very successful formula. I attended the very first Congress held in Bournemouth on 7-9 November 2006 and many others subsequently. These events provided the perfect forum for networking, exchanging ideas and sharing information with all those involved with dementia.

One needed good stamina though for the long days and even busier nights! I have fond memories of evenings spent in the bar with the aptly named 'hardcore' group of Admiral Nurses. I'm still surprised we were never thrown out, in particular one late evening in Bournemouth when Dave Bell led a hearty sing-a-long demonstrating in fine voice how music enhanced his therapeutic work!

The Journal of Dementia Care was launched by Dr Richard Hawkins and Sue Benson in 1993, the year before the Dementia Relief Trust was established. The Charity benefitted from many articles published in the Journal, which became an excellent resource for all those working in dementia care, as well as family carers.

In late 1994 Admiral Nurse Penny Dodds appeared on the Journal's front cover. Penny also featured on one of the posters designed for the Charity's official launch the same year, photographed wearing the crash helmet she wore riding her motor bike to visit clients. This certainly projected a new and modern image of nursing! Penny has recently returned to Dementia UK in the role of Academy Lead Admiral Nurse (Clinical Supervision).

The official launch of the Charity was mentioned in the March/April 1995 issue. The same month yet another Admiral Nurse, Riverside Team Leader Elaine Liburd, also featured on the front cover. There were many articles over the years featuring the various stages of the Charity and the development of Admiral Nursing. Admiral Nurse Madeline Armstrong, who led the team in Kent, later joined the Journal's advisory board.



The Charity welcomes a new Chief Executive



Barbara Stephens

Barbara joined the Dementia Relief Trust as Chief Executive in October 1999, having worked in a variety of voluntary sector organisations spanning a range of fields of interest including dementia, relationship counselling, criminal justice and alcohol abuse.

Barbara was well placed for this specific role having worked as a Regional Development Officer for the Alzheimer's Society from 1988–1992. At that time Alzheimer's disease was not widely recognised and the Alzheimer's Society, formed in 1979 by a group of family carers, was still in its infancy.

Barbara's interest in dementia was motivated by personal experience in her own family. Throughout her time at the Charity she maintained a belief that learning from people with lived experience was fundamental to Admiral Nursing practice and that family carers should be regarded as 'partners in care'. This combination of understanding and experience made Barbara ideally suited to accept the challenge to grow the Charity and widen the geographical reach of Admiral Nurses.

Barbara and I worked closely together for fourteen years to raise the profile of the Charity and increase the number of Admiral Nurses, overcoming many hurdles along the way. No task was considered too menial, anything from organising agendas to stuffing envelopes late into the night, we did it. After any late meeting we could be found unwinding in the Cobden Arms for a glass or two.

"Growth was the goal"

Barbara Stephens



"It was a hard time – trying to establish the model – trying to get people to believe in it"

Barbara Stephens

Further developments in Admiral Nursing



New teams in the North West and the West Midlands

At the turn of the Millennium, the Dementia Relief Trust embarked on an ambitious growth plan, which heralded new developments in London, Kent, the North West and the West Midlands.

Launch of North West Development 2000

In 2000 new services were established in Manchester, Preston and Bolton spearheaded by Colin Dugdale a senior mental health nurse who was seconded to the Trailblazer role from August 1999-July 2001. These teams were announced at a major national conference organised by the Charity in Southport. Colin was based at the NHS North West Regional Office, supported by the then Director of Nursing for the North West Regional Health Authority Professor Jean Faugier. Between October 2001 and November 2004 Professor Faugier joined the Charity's Board.

Support for the Admiral Nurses was provided by Alison Soliman and Walter Wills from the Charity's London base.

"It was extremely difficult to expand but nevertheless against all the odds we did manage to do so"

Ann Windiate

The Charity's 'Partners in Care' Launch Conference in Southport March 2000

The conference was attended by a large contingent from the Charity, including Monica Greenwood, Barbara Stephens and myself. Many of those who were soon to become Admiral Nurses also attended. It generated a new raft of publicity away from London and the South East and increased interest in the evolving Admiral Nurse model.

The conference was addressed by eminent family carer and dementia activist, the late Barbara Pointon. Barbara, who cared for her husband Malcolm with young onset dementia, had received high-profile attention in the autumn of 1999 for the TV documentary 'Barbara and Malcolm: a love story'. Barbara highlighted the plight of family carers by explaining the potential benefit a specialist nurse *would* have been to her, her husband and family. An inspiring speaker, Barbara later became a welcome Ambassador for the Charity.



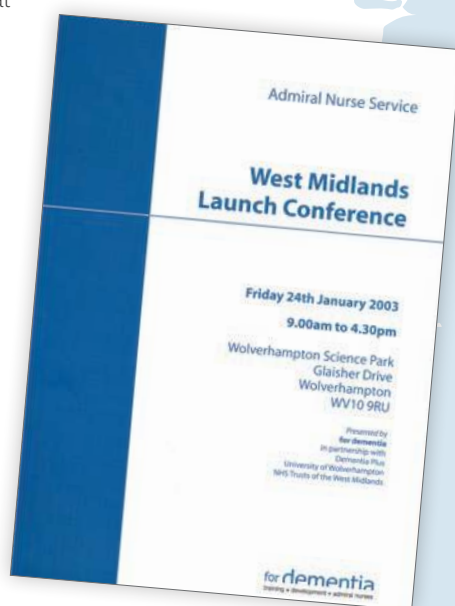


Launch of West Midlands Development – 2003

Following on from the success in the North West a fresh cohort of Admiral Nurse services was launched in 2003. Trailblazer Tony Braker, a mental health nurse, was supported by Professor David Jolley and Kate Read at Dementia Plus – situated at the West Midlands Dementia Development Centre. Barbara Stephens commented, “They were really pivotal people at the time and that started a wave of interest nationally”. New partnerships with NHS trusts were formed and services established in Worcestershire, South Birmingham & Solihull and North Warwickshire.

West Midlands Launch Conference in Wolverhampton 24 January 2003

I spoke at the West Midlands launch conference held at Wolverhampton Science Park. Susan Ashcroft-Simpson, Admiral Nurse team leader from the Manchester Service, gave a presentation on Admiral Nursing and Barbara Pointon again gave a powerful keynote speech. It was now our continuing role to persuade others of the increasing value of the Admiral Nurse Service. These service developments outside of London and the South East were a milestone and major achievement for the Charity.



Trailblazers and Pioneers

Colin Dugdale was appointed to the first Dementia Trailblazer post in August 1999. Colin's remit was to develop new Admiral Nurse Services across the North West, supported by Regional Nurse Lead, Professor Jean Faugier. Colin's work led to the creation of new Admiral Nurse teams in Manchester, Preston and Bolton. These new Services were widely welcomed. When Colin's secondment came to an end, the new role of Dementia Pioneer was created and Ted McGuinness was appointed in November 2003.

Tony Braker was appointed as Dementia Trailblazer for the West Midlands, for a fixed term of 18 months. Tony led the initiative for new Admiral Nurse teams to be established in Worcestershire, South Birmingham & Solihull and North Warwickshire.

Dementia Trailblazers and Dementia Pioneers became the Charity's approach for promoting growth in geographical regions. Later this included diversifying Admiral Nurse models and exploring how Admiral Nurses could work effectively in different health and care settings, offering the unique contribution of working practically and therapeutically with family carers as the primary focus.

As the Charity grew, Dementia Trailblazers and Pioneers were organised into the 'Development Team' with a wide remit across all strands of the Charity's work, including training. Pioneers and Trailblazers who were part of this endeavour included Dr Melanie Porter-Turner, Peter Irving, Jacqui Wharrad, Wendy Weidner, Hilary Woodhead, Christine Gillham, Emma Hewat and Julia Burton-Jones.

Strategic changes at the Charity resulted in the discontinuation of these roles in 2013, in favour of a more robust 'business' approach, which would see consultant Admiral Nurses more pivotally involved in stimulating growth and interest in Admiral Nursing.

Admiral Nurses working in different roles and settings

As interest in Admiral Nursing grew, both within the NHS and more widely, different models and approaches emerged. Traditionally, Admiral Nurses had been placed in older people's community mental health services.

The first Admiral Nurse to be appointed within a care home setting was Cheryl Rothschild, with Friends of the Elderly in 2008. Later she was joined by Vincent Goodorally who had previously worked as an Admiral Nurse with the Kingston Service.

Bupa invested in Admiral Nurses for their care homes, under the leadership of Dr Clive Bowman and Graham Stokes, which enabled Admiral Nurses to deploy their knowledge and expertise across the Bupa network of care homes.

Orders of St John Care Trust also introduced Admiral Nurses to their care homes in 2009, appointing Angie Williams as the first Admiral Nurse to work with OSJCT following models of practice pioneered by 'My Home Life' at City University.

Admiral Nurses were also introduced into community organisations: Rikki Lorenti was recruited as an Admiral Nurse by the charity 'Younger People with Dementia in Berkshire' and Kathryn Penrith was appointed by 'Making Space'; both posts were funded by a strategic grant from People's Health Trust Lottery.

The first Admiral Nurse was appointed to a hospice in 2012: Jacqueline Crowther worked on a research project with St Luke's Hospice.

Jeni Bell, appointed in 2009, led the Admiral Nurse Service in Southampton based within primary care. This Service was hosted by Southampton City Primary Care Trust and launched at Southampton Football Stadium in 2010. Subsequently, Jeni was appointed to an Admiral Nurse role with Southampton General Hospital in 2012. This was the first Admiral Nurse post to be based in an acute hospital.

Royal British Legion – Admiral Nurses

The partnership formed in 2010 with the Royal British Legion (RBL) proved to be a significant one for Dementia UK. The appointment of the first Admiral Nursing Service for veterans and their families took place in the North West and later developed into other parts of the country including the West Midlands and South West.

North West Dementia Pioneer Ted McGuinness's role was to support the existing nurses and develop new Admiral Nurse Services in the area. He led the collaboration with RBL, which is now a significant national service, hugely valued by people with dementia who have served in the forces and their families.



Paula Smith had opened the Admiral Nurse Service in Bolton and was still in post when it sadly closed twelve years later. Paula and another of her original team moved across to the new team being planned with the Royal British Legion (RBL) in Lancashire, one of the first in a charity setting. Since they were both experienced Admiral Nurses they were able to open up the Service smoothly.

There are now thirty Admiral Nurses with RBL, and the growth of these teams has been easier due to generous support from this large charity.



On Saturday evening 7 November 2015, Admiral Nurses featured as part of RBL's charity work at the Festival of Remembrance, held annually at the Royal Albert Hall in the presence of the royal family. It was an incredible coup for Admiral Nurses to appear on primetime television. Although the unprecedented publicity was much welcomed it meant

the increased volume of calls caused severe disruption in the office the following week! The office team was still relatively small and several volunteers were recruited to keep up with the volume of enquiries.



Admiral Nurse Competency Framework

In 2001, the Dementia Relief Trust funded an action-research project with the Royal College of Nursing (RCN) to develop a competency framework for Admiral Nurses. The aim was to distil from the practice of Admiral Nurses a detailed description of their role, broken down into component parts, so that their role could be better understood and evaluated.

Vicky Traynor was appointed as Research Fellow and the project was overseen and led by Jan Dewing from the RCN. Vicky worked alongside all the Admiral Nurses, observing their interventions with families and interviewing family carers about what was valuable about the support provided by Admiral Nurses.

The result was the creation of a 'handbook' detailing the skills and attributes that would be expected of Admiral Nurses for quality assurance and to act as a guide to their professional development.

The 'Competency Framework' formed the basis of the practice development strategy that was developed by Consultant Nurse, Emma Pritchard, and Rachel Thompson, who was appointed as 'Practice Development Lead' in 2004.

The first tranche of regional practice development nurses were: Pam Kehoe (North West), Joan Devenny (Kent), Victoria Lyons (London) and Bob Graham (West Midlands).

The 'Competency Framework' was launched on 16 September 2003 at an evening event at Novartis House, Portland Place in London, addressed by John Tait OBE (Trustee) and Dr Kim Manley from RCN (both pictured here with Barbara Stephens).

Dementia UK Chief Nurse & CEO Dr Hilda Hayo:

"The Admiral Nurse Competency Framework was revised in 2016 by the Association for Dementia Studies, University of Worcester in collaboration with Dementia UK to meet the changing expectations of Admiral Nurse Services. The Admiral Nurse 'Competency Framework' enables Admiral Nurses to develop and maintain an ongoing professional portfolio of collected evidence about their practice."



John Tait OBE

The late John Tait joined the Board of the Dementia Relief Trust in 1997 and was a pivotal influence in the early days of Admiral Nursing. John's professional expertise in mental health nursing made him the perfect chair of the Admiral Nurse Service Advisory Committee (ANSAC), a role that he fulfilled for several years. John led the first wave development of Admiral Nurse Services in the North West. John was Deputy Chief Nurse for England at the Department of Health from the mid-1980s until 1996, having started his career in nursing as a psychiatric nurse and progressed through the ranks. John served as a Trustee for the Dementia Relief Trust until his untimely death in 2006. John's extensive networks in health and social care and the respect he commanded at the highest level brought immense benefit to the Charity at a critical time in its history.

Dementia UK Head of Research and Publications Dr Karen Harrison Denning explains how the model of Admiral Nursing was adapted to contemporary health and social care:

“Admiral Nurses were initially required to be registered in mental health. Over time it became apparent that people with dementia and their families had needs that demanded a wider range of skills and knowledge beyond just mental health. In 2013 Dementia UK responded by opening up the eligibility for Admiral Nursing, embracing nurses from Adult Nursing and Learning Disability Nursing who had the appropriate knowledge, competencies and skills to become an Admiral Nurse.”

Senior Admiral Nurse roles

Inspired by the work of Professor Tom Kitwood at Bradford University in the mid-1990s, growing numbers of health and care professionals became interested in dementia in the years that followed. Career pathways in dementia across a range of disciplines began to evolve, and fresh attention was paid to Admiral Nurses as aspiring leaders in this field. This fuelled the Charity's appetite for growth and led to the creation of new Admiral Nurse roles offering higher-level education and research opportunities.

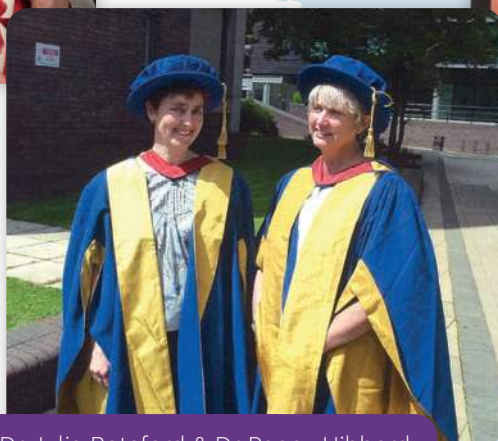
Julia Botsford took up the new post of **Admiral Nurse Lecturer/Practitioner** in 2001, working with Moira Sugden at Middlesex University on the Advanced Diploma and practising as an Admiral Nurse as part of the Haringey team.

Penny Hibberd was appointed to a similar Admiral Nurse Lecturer/Practitioner role with Canterbury Christ Church University in 2004.

The first **Consultant Admiral Nurse** post was created in 2003 in partnership with Central and North West London NHS Foundation Trust. Emma Pritchard was based with the Admiral Nurse team in South Kensington and contributed to practice development at the **for dementia** office in Camden. Karen Harrison Denning was appointed as **Consultant Admiral Nurse** based in Haringey (for clinical work) with an academic link to UCL where she undertook her PhD in end-of-life care and dementia.



Dr Karen Harrison Denning



Dr Julia Botsford & Dr Penny Hibberd



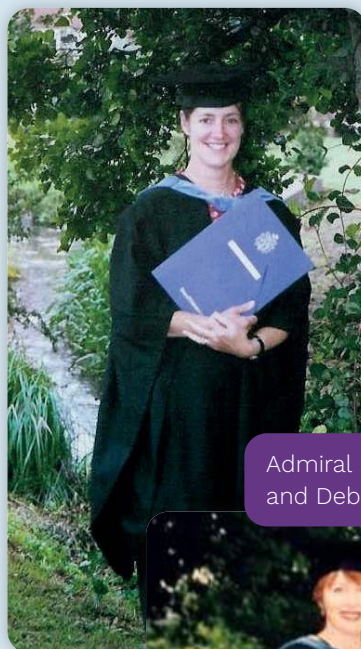
Dr Juanita Hoe



Juanita Hoe was appointed as an **Admiral Nurse Research/Practitioner** in July 2004 working clinically in Redbridge and lecturing and studying for her PhD with Professor Martin Orrell at University College London. Juanita was awarded her Doctorate in Mental Health Sciences in October 2007, receiving her PhD on 5 September 2008.

An important part of the Charity's work is to invest in the development of Admiral Nurses and encourage a deeper understanding of relationship-focused interventions that make a difference to a person's experience of dementia and its impact on the family.

A special interest group focusing on palliative care needs of people living with dementia was established in 2008, involving Karen Harrison Denning and a number of other Admiral Nurses, and Jacqui Wharrad, Dementia Pioneer. The group worked with Admiral Nurses and carers to evaluate best practice in end-of-life care for people with dementia. This resulted in the creation of an Admiral Nursing pathway, for which an accolade was awarded at the 'National Palliative Care Awards' in 2010.



Admiral Nurses Alison Coignard and Debbie Hawkins graduating



A new image for the Charity

First Charity Rebrand – *for dementia* 2003

The original name chosen for the Charity, the Dementia Relief Trust, began to feel outdated. Some also felt the name did not accurately describe the Charity's work or connection with Admiral Nursing.

Although the Board was keen to enhance the Charity's image, we were once again operating on a tight budget so we accepted the generous offer from Jonathan Eastwood and his agency Immaculate Conceptions (pictured above) to help the Charity on a pro bono basis. The aim was to find a solution which illustrated the various strands of the Charity under one banner.

for dementia was adopted as the Charity's new name at the AGM on 12 December 2002 and the Charity prepared to launch the new identity at its West Midlands Conference on 24 January 2003. An official event was later held to mark the rebranding at the Royal College of Physicians on 17 March 2003.

A presentation was made in the theatre followed by a reception in the presence of Charity Patrons and the Lord Mayor of Westminster Frances Blois.



However, over time we realised we were possibly trying to be too clever in our choice of new name. ***for dementia*** worked well with the sub-headings – training, development, admiral nurses – but the lowercase title proved to be a problem when used in isolation. When Charity Patron, novelist Joanna Trollope, declared she found the name impossible to fit into a sentence, I was prepared to admit defeat!

Renaming the Charity - Dementia UK 2010

After only a few years, therefore, the decision was made to rename the Charity once more. The name Dementia UK had been considered earlier but it could not be justified until there was a steady development of Admiral Nurse Services across the country. Once again the Charity did not have the resources required for a major makeover but in 2010 decided it was time to move on from previous mistakes. The renaming occurred relatively quietly and at little cost to the Charity.

“Changing the name from *for dementia* to Dementia UK was game changing”

Barbara Stephens

for dementia has changed its name to Dementia UK

Dementia UK

Improving quality of life

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Registered charity no: 1039404



Dementia UK
Improving quality of life



How you can support
Dementia UK



We made it to 10!

The Charity's 10th Anniversary Year 2005

The Charity held various events to mark its special Anniversary year. Tin or aluminium is the symbol of this decade. These materials represent the strength and resilience required to sustain the union. This seemed appropriate since the very same qualities were similarly to be found in Admiral Nurses and those working with the Charity. It is important to mention that on this occasion a decision was made to celebrate the official launch of the Charity in 1995 rather than its registration the previous year. The main reason being that the Charity's still small team was not fully prepared for the exciting schedule planned to take advantage of this milestone.



During the Anniversary year, encouraged by Admiral Nurse Victoria Lyons (Mulkerrin), an intrepid team including Admiral Nurses and **for dementia** staff, comprising Jackie Aird, Tony Braker, Gigi Burgdorf, Claire Hawman, Jules Jones, Jenni Mowbray, Victoria Mulkerrin, Lynsey Seaholme and Cathy Whiteman all took part in a tandem skydive raising substantial sums from sponsorship. 10 skydivers jumping 10,000 feet to celebrate 10 years!

Andrew Lyons (pictured far left, in red) had driven his then girlfriend Victoria Mulkerrin to the airfield when, as a replacement for one of the Nurses he unexpectedly found himself literally 'up in the air' in order to fulfil the Charity's original plan. Now married, Victoria reminisces "it was all part of the marriage test!"

Anniversary Breakfast

Launch Event

We launched the year with an Anniversary Breakfast Reception. The presentation was in the form of a news bulletin delivered by Charity Patron Martyn Lewis, and Anniversary Ambassador Katie Derham on 27 January 2005 at the Imagination Gallery. It had been agreed this was an opportunity to celebrate and showcase the Charity's achievements over the last ten years. We had overcome several minor squalls and though not yet quite out of the storm, it began to feel this might be possible in time.

for dementia Patron Joanna Trollope talked about the stigma surrounding dementia and the importance of heightening awareness in order that issues may be brought into the public arena. Newly appointed Professor of Admiral Nursing, John Keady, also attended the event. This Chair position was based at Northumbria University and, together with Professor Charlotte Clarke, at that time Head of the Department at Northumbria, John spoke about the scope of the role and the opportunities for further advancing Admiral Nurse practice.

Amongst those attending this event was the late Dr Thomas Stuttford, a medical doctor journalist and politician. As a medical correspondent Dr Stuttford was interested in the Charity and the support offered by the Nurses. He wrote an article which appeared in the Times a few days later, mentioning the Charity, Admiral Nurses and my father, the Admiral in his naval-style hat.

Special Anniversary notepaper and newsletters were designed including the names of the ten Anniversary Ambassadors chosen: Richard Baker, Jo Brand, Professor Charlotte Clarke, Katie Derham, Leonard Fenton, Daniel Green, Victoria Mather, Harland Miller, Barbara Pointon, and Bob Woods.



When articles generated increased publicity for the Charity, we were not always equipped to deal with the amount of interest these produced. On these occasions we relied on volunteers to help, answer the phones and reply to email enquiries from carers desperately wanting to know where they might access an Admiral Nurse.



10th Anniversary Carol Concert at St Margaret's Church Westminster Abbey followed by an End of Year Reception at the House of Lords on 6 December 2005

Earlier in 2005 a Reception hosted by Vicky and Anthony Wilson was held at the Freemasons' Hall, in order to recruit additional volunteers to the Event Committee required to step up to the challenge of selling 750 tickets for a special 10th Anniversary Carol Concert.

Thanks to Vicky and her newly recruited extended committee the anniversary year ended in spectacular fashion with a Carol Concert for 750 guests at St Margaret's Church, Westminster Abbey.

This prestigious event marked the end of a significant milestone year in the Charity's history. Guest readers included actress the late Dame Diana Rigg and Charity Patron Joanna Trollope. Dom Antony Sutch, who gave the Address, had been identified by Vicky and me after we had both heard him offer his 'Thought for the Day' about carers on BBC Radio 4's Today programme. We both agreed he would be the perfect choice for this prestigious event. Approximately £30,000 was raised for the Charity, almost trebling what we had made previously.



Afterwards, a smaller Reception was held in the Cholmondeley Room at the House of Lords, kindly hosted by Lord Haskel. Guests were welcomed by two of our Charity Patrons, Katie Derham and Jim Broadbent, who both spoke movingly about their mothers' experience of dementia. I announced my retirement as Chair of the Board that evening, introducing Vicky Wilson as the new Charity Chair elect.

I was extremely touched to receive a stunning bronze sculpture entitled 'Help at Hand' presented to me by my close friend and colleague Hilary Leslie. I am pictured with the artist Anne-Laury Dizengremel. As Hilary amusingly stated in her speech, "We could have given her a carriage clock" but wishing to be more original they researched this most thoughtful gift. The sculpture now sits at home appropriately on a desk which belonged to my father.



The Carol Concert is an important event in the Charity's calendar, and continues to this day, organised by an outside committee of volunteers supported by the Charity's fundraising team. This successful annual event now raises a remarkable six figure sum each year towards the work of the Charity. The contribution of all those who have been involved in the organisation of this event since its inception is hereby gratefully acknowledged.

The 'Remember a Star' page in the Carol Concert programme was introduced around this time and proved very successful. Sponsoring a star for the Christmas Trees in the church, the names of a family member or others affected by dementia would be featured in the Concert Programme. Admiral Joe, or Grandpa Joe if entered by one of the grandchildren, is remembered in this way every Christmas.

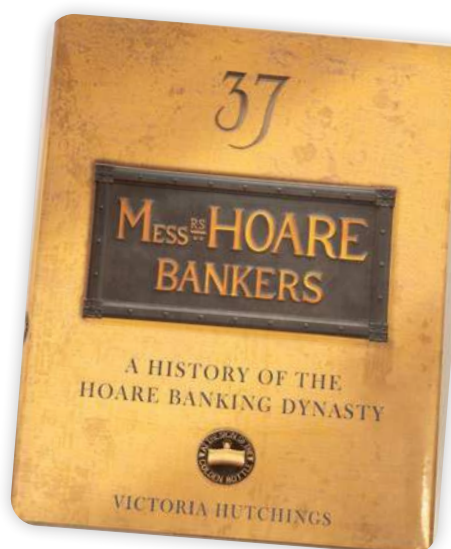




Victoria Hutchings pictured top right with other members of an early Carol Concert committee

Hoare's Bank Private Dinner – July 2006

Victoria Hutchings was museum curator of Hoare's Bank for twenty years. She was already a supporter of the Charity prior to introducing her sister Joanna. The Hoare family generously sponsored a Private Dinner for a group of the Charity's supporters in July 2006 at the bank in Fleet Street, where guests were offered an opportunity to view the bank's private archive collection. The evening raised further funds for the Charity, including a very generous donation from the Hoare family.



“Given the effects and consequences of the pandemic it is commendable and wonderful that any charity survives. I salute Dementia UK warmly, and wish it nothing but well for the future”

Joanna Trollope

Joanna Trollope CBE – Patron

I was introduced to the author Joanna Trollope by fundraising committee member the late Alison Pimlott, a friend of Joanna's sister Victoria Hutchings who had joined the Carol Concert committee. It was truly wheels within wheels, as Alison had in turn been introduced to the Charity by my friend Kathryn Sanders. Alison and I met Joanna for tea at Brown's Hotel, where immediately understanding the need for Admiral Nurses Joanna graciously agreed to become a Patron. Both Joanna and Victoria's father, like my own, had succumbed to vascular dementia, cared for by their mother for several years.



The Second Decade

It seemed a great achievement to have come this far; everyone was encouraged and more determined than ever to continue moving forward. There were so many wonderfully loyal, enthusiastic people on board that although we continued to experience the odd 'sink or swim' moment no one was giving up.

Introducing the Helpline Admiral Nursing DIRECT

Admiral Nursing DIRECT now Admiral Nurse Dementia Helpline

The publicity generated by the renaming of the Charity to **for dementia** led to increasing demand for the Service from across the country. The challenge faced by the Charity was how to expand the availability of Admiral Nurses rapidly.

The helpline service started with Madeline Armstrong answering telephone calls at the Charity's head office in Camden, one day per week. When family carers called on days when Madeline wasn't there, they were encouraged to call back on 'Madeline's day', which meant that Madeline became very busy, and in just a few weeks, her working hours were increased and she was joined by Rachel Thompson, also part-time.

In 2006, Jules Jones was seconded from her post as team leader with the Hillingdon Admiral Nurse Service, for one day per week, to lead the development of the helpline. The Admiral Nurse team leaders came up with the name 'Admiral Nursing DIRECT'. Jules put systems in place for recording the work of Admiral Nurses on the helpline. A rota of Admiral Nurses

was drawn up, initially on two evenings per week, in addition to the daytime work provided by Madeline and Rachel. Jules organised training in helpline skills, recognising that these one-off interventions required a far different approach from working as an Admiral Nurse face-to-face in the field.

As awareness of this service grew, people from all over the UK (and beyond) contacted the helpline for advice and emotional support. As well as enabling many more families to receive help from an Admiral Nurse it provided compelling evidence for the need to invest in more Admiral Nurses in local areas.



Launching the Helpline

The Charity returned to the Imagination Gallery once more on 27 February 2007 to launch this exciting new project.

The event was hosted by Patron Katie Derham and attended by many of the Charity's supporters including TV Presenter Fiona Phillips and the late Leonard Fenton. Project Lead Jules Jones coordinated a series of presentations from Admiral Nurses and others, demonstrating the range of enquiries and requests for help to which the helpline was responding. The launch event served to raise the profile of this important new service.

Having heard Diana Melly speak about her role caring for her jazz musician husband George, another article, written by Dr Thomas Stuttford, appeared in the Times on 1 March 2007. As already illustrated, any new publicity prompted an immediate reaction, with many family carers approaching the Charity seeking support. Once the Admiral Nurse Dementia Helpline was properly established, we were better able to respond, relieving the pressure on our office and those Nurses answering calls.

It should be mentioned that in 2019 the Admiral Nurse Dementia Helpline won the 'Helpline of the Year' Award at the Helplines Partnership Annual Awards, celebrating the achievements of helplines around the UK. Susan Drayton, Clinical Lead of the Helpline, also received third place in the 'Employee of the Year' Award as well as the 'Random Acts of Kindness' Award, she shared with her dedicated team.



From very early on Admiral Nurse teams have won both individual and team awards in recognition of the vital support offered to families living with dementia. They are too many to list here but the Charity continues to be proud of their achievements.



Events continue to promote the Charity

Fundraising events continued during the next decade, although as the Charity grew the understanding of Admiral Nursing and the need to support carers was becoming more recognised, making any approach to grant-giving trusts and foundations a little easier. Many opportunities which arose were time-consuming to organise, and there was so much more to do. Even though their cost effectiveness was questioned individual events remained an excellent way to advertise the Charity's work.

ICAP CHARITY DAY 7 November 2007

A surprise introduction from Andrea Gover to Michael Spencer, now Lord Spencer, then Chairman of ICAP, one of the largest global broking firms, led to the Charity's participation in their annual Charity Day. **for dementia**, as the Charity was then, was fortunate to be selected as one of the beneficiaries for 2007. Several of our Patrons attended this prestigious fundraising day. The late Leonard Fenton, best known for his role as Dr Legg from the cast of the popular television series EastEnders, proved especially popular. The Charity was grateful for a most generous donation of £150,000 from the day.

Leonard Fenton – Patron

The late Leonard Fenton gained nationwide fame through his role as Dr Harold Legg, one of the original characters in the popular BBC soap opera EastEnders, a part he played for 34 years. Leonard was also a serious stage actor appearing at the Royal Court Theatre and spending time with the Royal Shakespeare Company. Several of the Charity's team spent an enjoyable evening at the Menier Chocolate Factory theatre invited by Leonard to watch his latest play. Leonard was introduced to the Charity when invited by CEO Barbara Stephens to become one of ten Ambassadors for the 10th anniversary year. Later as a Patron he attended several events, including the Training Awards, the Launch of the Admiral Nursing DIRECT Helpline and Carol Concerts. Leonard was a wonderfully kind Patron who has been greatly missed.



A proud day for the Charity

Jane Jason OBE – June 2007

It was certainly a surprise to be awarded an OBE for services to charity in the Queen's Birthday Honours in June 2007. I considered the award a great honour, not only for me personally but also for the Charity and all those who had contributed to its success. It was a very proud day when I was joined by my family for the Investiture at Buckingham Palace on 23 October 2007.



Melly & Friends

George Melly at The 100 Club 10 June 2007

I named this my 'Challenge Anneka' moment. We felt very much like those in the popular television series, an entertainment reality programme hosted by Anneka Rice who, with her positive attitude and unfailing ability to encourage and nurture community spirit, regularly faced completing near-impossible projects in record time.

The George Melly event, originally scheduled for late July, already had a tight time frame but the date had to be brought forward due to a deterioration in George's health. This left the Charity with less than six weeks preparation time. As always, the **for dementia** team was up for a challenge and sprang into action. As well as recruiting several volunteers as ushers for the evening, sponsors were found, auction and raffle prizes donated, a souvenir programme produced and commemorative T-shirts printed and the creation of a CD of the evening was also organised.

We were grateful that the 100 Club organised the sale of the majority of tickets to George's fans. Jazz fans and Charity supporters lined the pavement down Oxford Street on 10 June 2007 to enjoy a very special evening of jazz with George Melly & Friends.

"It was an amazing event – and those lovely T-shirts"

Diana Melly



The evening, compered by Manfred Mann frontman Paul Jones, also featured George Webb and his Band of Brothers, and Kenny Ball and his Jazzmen. Alan Yentob, then creative Director at the BBC, acted as auctioneer raising significant sums for the Charity during the interval. George's distinctive J&B striped suit sold for an impressive £1,200.

The highlight of this emotional evening was George Melly's performance. Brought on to the stage in his wheelchair, and encouraged by his wife Diana, he sang three songs including 'Ol' Rockin Chair' accompanied by Digby Fairweather and his Half Dozen. George left the stage, on what was to be his final appearance, to a standing ovation, bringing to a close his exceptional career. It was an impressive performance in spite of his obvious frailty. Those not in a hurry to leave were later treated to yet another jazz session including some extraordinary impromptu harmonica playing from Paul Jones. George sadly died some three weeks later.



Memorial Jazz Lunch at Pizza on the Park in September 2007

There was a follow-up Jazz Lunch event at the Pizza on the Park which I sadly missed. I believe there was lots of jazz and reminiscing about George.



"I remember thinking I wonder if anyone will come. When we arrived there was this huge queue down Oxford Street and I thought it's going to be great!"

Diana Melly

Diana Melly – Patron



Diana Melly made it known in early 2007 that her husband jazz singer George had vascular dementia as well as a diagnosis of lung cancer. Diana described the support received from Admiral Nurse Madeline Armstrong as a lifeline and agreed to speak about her caring role at the launch of the helpline 'Admiral Nursing DIRECT'. Diana then helped organise the very successful jazz evening for her husband George. After George's death, Diana volunteered at the Charity, becoming a Patron later the same year.



The Second Lord Mayor of Westminster's Mayoralty – Cllr Louise Hyams – May 2008-2009

The Charity was once again chosen as the beneficiary of the Lord Mayor of Westminster's year of office. Councillor Louise Hyams had learnt about the Charity from Michael Brahams. Louise was particularly keen to maintain the focus on family carers during her year since her own mother had dementia.

Once more we planned a calendar of events but Louise's choice to focus on family carers meant the year would pan out rather differently to that of the previous Lord Mayor we had worked with. It was thought a tea party idea we were considering would work well. I had been mulling over the idea for some time.

In June 2003, the Charity had celebrated Carers Week in traditional style with a small gathering of family carers for Tea at Fortnum and Mason. This had planted the seed for what was to become a much larger annual event. I had often contemplated that a campaign similar to the Macmillan Coffee Mornings would be a simple and effective way to involve carers. These events enable carers to support the Charity but at the same time enjoy a welcome break with family and friends. Louise's Mayoral year would be a great platform from which to quietly launch this proposed national campaign.

Tea Party

'A Tea Party to Remember' was arranged for 2 February 2009. Sadly, that morning, as luck would have it after heavy snow throughout the night, the city was reduced to a total standstill! Much to everyone's disappointment the event had to be rescheduled. Planned as an opportunity to launch the Tea Party idea, we had notified carers inviting them to host events as well as encouraging care homes to participate. However, we didn't want to lose momentum, so we were not going to give up.

The rescheduled tea party was held a month later in the Lord Mayor's Parlour at Westminster City Hall on 3 March 2009. It proved highly successful and was thoroughly enjoyed by us all. The delicious tea produced by the Parlour's superb caterer Jenny Bianco made us all feel thoroughly spoilt. Family carers, the late Helen Fowler and Michele Poole, who had made the journey all the way from Worcestershire, amused everyone with an account of their own local event, held on the correct day in spite of the inclement weather, showing the indomitable spirit of carers. Sue Cohen then spoke about her beautifully illustrated new book 'Time for Tea'.



Sky Dive

The highlight and personal achievement of the year had to be the Sky Dive which finally took place on 1 April 2009 when a very brave Lord Mayor of Westminster fulfilled her promise.

She admits to being very nervous when it came to her turn saying: *"I could see the ground below. However, once I was falling through the air it felt truly exhilarating."* They raised over £10,000 for the Charity that day so, in spite of her initial anxiety, Louise admitted: *"It was worth risking my life for."*



Other Nurses managed to complete their jumps at other times and in May, Tom Melly, son of Diana and the late George Melly, made a skydive, generously donating the amount raised from sponsorship to the Charity.

Reception at the Ritz

The Lord Mayor of Westminster's charity was generously offered the use of the elegant William Kent House at the Ritz Hotel. An evening Reception was held on 17 February 2009. Many **for dementia** supporters attended to learn more about the Charity.

My brother Peter spoke about the Charity and introduced television presenter and journalist John Suchet who spoke publicly for the first time about his wife's dementia and the support he had received from his Admiral Nurse. His television and radio appearances on the same day brought unprecedented publicity for the Charity and Admiral Nurses.

Final events in the Mayor's Parlour:

The final events to take place in the Mayor's Parlour were a lunch hosted by Louise for friends and colleagues and the End of Year Reception when the Charity was presented with a cheque for £104,664.59. The Charity was once more immensely grateful for the support received from everyone at Westminster City Hall.

It proved to be another enjoyable and equally successful year. At the end of her Mayoralty Louise accepted the invitation to join our growing list of Patrons.

Designers' Pantomime 12–16 October 2010

Louise's year in office had prompted the Charity's involvement in two successful events. Firstly, the Designers' Pantomime, secondly the introduction of the Charity's annual tea party event – which became 'Time for a Cuppa'.

At the Reception at the Ritz, Bill Bennette introduced us to fellow designers Tim Gosling and Fameed Khalique who were producers of the bi-annual Interior Designers' Pantomime. The following year we were delighted to learn that the Charity, now Dementia UK, had been chosen as the charity to benefit from funds raised at the 2010 production of 'Snow White and the Seven Designers' which was to run for five evenings at the Garrick Theatre. This was far more ambitious than previous pantos held more informally at Kensington Town Hall where the designers strutted their stuff at little expense, donating all proceeds to the named charity.



A committee was formed, chaired by then trustee Andrea Gover, assisted by Event Co-ordinator Claire Curtis (now Ferris) from the Charity, to organise A Gala Dinner and Auction for 400 to be held at the Banqueting Hall, Whitehall after a performance of the pantomime on 14 October.

My exclusive responsibility was the organisation of transport from the theatre to the dinner venue, so I was very relieved to see double decker buses lined up along Charing Cross Road to transport all the dinner guests. That evening had been a traffic nightmare as several roads in Whitehall had been closed and traffic redirected. Many had experienced travel difficulties – even the Charity's Chair Ann Windiate was forced to hire a cycle rickshaw to ensure arriving in time for curtain up! The show's run was extremely hard work for both the cast and the Charity but we were incredibly grateful that over £100,000 was raised.



Time for a Cuppa officially launched 2010

Following on from the very first tea party introduced during Louise's Mayoralty the previous year, when family carers and care homes had been successfully encouraged to hold events of their own, it was decided to develop this idea seriously. A business plan was drafted and a small committee was formed, headed by Claire Curtis (Ferris), now part of the Charity's Business Development Team. The committee was supported by Will Brewster, at the time from Flagship Consulting, and Rhonda Smith of Minerva PR to increase the scope of both supporters and sponsorship.

We discovered our original choice of name for the campaign 'Care for a Cuppa' had already been taken by another charity so eventually, after much discussion, the new title – 'Time for a Cuppa' – was agreed. Fiona Phillips, who was unfortunately unable to attend the previous year's rescheduled event, agreed to become the first Patron of the tea parties.

The first official Time for a Cuppa tea party took place on 1 February 2010 in the Reception Room of The Council House in Westminster. It was an opportunity to explain about this proposed annual event to all the carers we invited. Time for a Cuppa was to prove a highly successful annual event taken up by an increasing number of families around the country each year.

Later in 2012 another Time for a Cuppa Event was held in the Strangers' Dining Room at the House of Commons hosted by Stephen Lloyd MP and sponsored by Barchester Health Care. Several carer supporters attended as well as Patrons Diana Melly, Louise Hyams and the late Leonard Fenton.



Time for a Cuppa has now become the Charity's flagship fundraising event raising a substantial six figure sum annually.



Phyllis Logan – Celebrity Ambassador

Celebrity Ambassadors now regularly promote Dementia UK events such as the annual Time for a Cuppa fundraiser. In 2013 Celebrity Ambassador Phyllis Logan, famous for her part as Housekeeper Mrs Hughes in the popular television series Downton Abbey, persuaded members of the cast to join her in promoting the event. Phyllis, who has personal experience of dementia, acknowledges the value of Admiral Nurses: *"I know many people would be in despair without them. I am pleased that their name has become much wider known and that the numbers are increasing. A remarkable achievement from such modest beginnings."*



Jane's 70th Birthday
Time for a Cuppa Tea Party



Dementia Cafés

Further opportunities for carers and their relatives to meet

Most people experience caring as a challenge at some time but it can also provide opportunities for strengthening a relationship. Regular meetings run as cafés or clubs were a relatively new idea thirty or so years ago. The clubs were informal gatherings for social engagement and peer support, offering carers a brief interlude in a safe environment. There must be many such schemes now, but in the early part of the Millennium these were innovative ideas. Well supported by family carers many were initiated by Admiral Nurses including those described here:

Kingston Dementia Café 2001



The Kingston Dementia Café set up in September 2001 was

an early Admiral Nurse initiative. The café was run with support by Admiral Nurses Jane Capus and Vincent Goodorally and twenty five participants would attend regularly each month. They arranged entertainment and special events such as Christmas parties and summer barbecues. In 2002 the café was runner up in the Community Care Magazine Awards.

Joe's Clubs 2005



These clubs were set up in Worcestershire and North Warwickshire in 2005 by Admiral Nurses and family carers. Admiral Nurses provided expertise and advice for family carers about the problems, challenges and rewards of caring for a relative with dementia. Joe's Clubs met weekly, offering a regular lifeline for family carers. This joint initiative was a finalist in the Nursing Times Awards' category 'Promoting Health in the Community' based on their work in developing the clubs in both counties.



Tom's Club 2009

This was a type of dementia café set up by Haringey Admiral Nurses in April 2009 providing peer support for family carers and access to the dementia expertise of Admiral Nurses. It was launched officially by the Mayor of Haringey on 10 June 2009. The Club was named after former Tottenham Hotspur footballer, Tommy Harmer, who, ironically had attended the Charity's launch in 1995, and who was cared for by his wife until his death in 2007. All monies collected at his funeral were donated to support the setting up of this project. The family was supported by the Haringey Admiral Nurses.



Carers continue at the heart of the Charity



Carers often have a strong desire to give something back

Carers were and still remain the mainstay of the Charity. Dementia UK is a charity formed by carers – for carers. From the early support received from members of CRAC Dementia there is now a growing number of Dementia UK Volunteer Ambassadors helping to raise the profile of the Charity and highlighting the Nurses' work.

Many carers are keen to support the Charity, even those who have not been fortunate to have received the support of an Admiral Nurse are not deterred from helping to create Admiral Nurse posts so others may benefit. I have been fortunate to meet in person some of those who have actively supported the Charity through its most challenging times.

“Admiral Nurses provided invaluable support so the last years have been ‘pay back’ time”

Helen Fowler

Ruth Tomkins BEM

Ruth's mother was a patient of Monica Greenwood who introduced Ruth to the Charity after her retirement. A successful interior designer Ruth had earlier helped Monica with the refurbishment of the day hospital for the first training programme in 1988. When she moved to East Sussex Ruth, pictured here third from left, teamed up with Jacqui

Wharrad, a Dementia Pioneer. In turn they were joined by Nick Carre, acting as Treasurer for the group, and another local resident Susan Harrison to raise funds for Admiral Nurses. In 2017 Ruth was awarded the British Empire Medal for services to carers and for her fundraising efforts.



Sheila Wainwright

Head teacher Sheila Wainwright cared for her husband after he was diagnosed with dementia in his late 50s. Sheila heard about Admiral Nurses too late but this did not prevent her from fundraising in her local area. Recognised with an Unsung Hero Award in her local community, Sheila spent six years establishing four Admiral Nurse posts in Wakefield, Yorkshire and another in a local hospice. She has given many presentations and represented Dementia UK at events such as the annual Carol Concert. Sheila is now supporting another worthwhile dementia related scheme, whilst continuing to support Dementia UK as a Volunteer Ambassador.

Jan Burt BEM

Like others, Jan never had the benefit of an Admiral Nurse but recognising their importance has been raising substantial amounts for Dementia UK since 2010. Jan has spoken about her caring role at official Dementia UK events and continues to raise funds at the Ball she organises annually at Broomfield Hall. This has helped to provide four Admiral Nurses covering the whole of Hertfordshire and another based in a local hospital. Jan received the British Empire Medal in recognition of her charity work and continues to represent Dementia UK as an official Volunteer Ambassador.

Lady Sally Grylls

Sally Grylls became involved with Dementia UK on the Isle of Wight in 2012. Having broken her leg, as an in-patient she experienced how people with dementia were being treated in hospital and was motivated to do something about it. She then heard Jim Broadbent's Radio 4 Appeal for Dementia UK. When contacting the Charity, she discovered Barbara Stephens the Charity's CEO also lived on the Isle of Wight so felt it was meant to be and set about raising funds for Admiral Nurses. Sally continues to lead the successful campaign to sustain Admiral Nurse posts on the island.

"After my husband died and I got my head round living again I thought 'you can sit on the settee or you can get up and do something worth doing'"

Sheila Wainwright

Worcestershire Carers

A close-knit group of enthusiastically active carers in Worcestershire and their neighbours in North Warwickshire should be recognised for their unwavering support and promotion of the Charity:

- **Jennie Hayward** was an active promoter of Admiral Nursing and held many fundraising events in her home.
- The late **Helen Fowler** was involved with many community and fundraising events with **Michele Poole** including many successful 'Time for a Cuppa' tea parties. I distinctly recall first meeting Helen and her husband Tony, dressed smartly in a navy blazer. He reminded me very much of my father.
- **Cheryl Hudson** was a very active carer at the time who, as well as supporting local fundraising and Joe's Club, was a member of the original steering group for the Worcestershire Admiral Nurses.

I should also say a little more here about the support the Charity received from the late **Barbara Pointon MBE**. Barbara was formerly Head of Music at Homerton College, Cambridge. She campaigned tirelessly, over many years often speaking up for the need for Admiral Nurses although she had never benefitted from their support. Barbara and her husband Malcolm came to the public's attention in 1999 when ITV first showed the documentary 'Malcolm and Barbara – A Love Story', the first time that dementia received that level of prominence on a main television channel. In 2004 Barbara won a landmark case arguing that the NHS should fund nursing care at home. In 2006 she was awarded the MBE for services to carers of those living with dementia. Barbara sadly passed away in June 2020. Barbara and I shared many a G&T together over the years; both her company and her support are sadly missed.

How lipstick helps

Volunteer Ambassador Jan Burt tells a lovely story which illustrates how carers continue to support each other. A man attending a carers' group wanted to help his wife. Her hair and makeup had always been immaculate so she became upset when no longer able to apply her lipstick. It concerned him greatly that he had been unable to help. Members of the carers' group willingly assisted, allowing him to practise on them so his wife could once more feel well groomed.

Sunshine in your smile

Admiral Nurse Penny Dodds wrote an article way back in 1994 in the Journal of Dementia Care headed 'Sunshine in your smile' explaining how lipstick can enhance a smile, and be an important communication tool.

A similar story led to **"Red Lippy Day"** in 2015. Jules Osmany started this fundraising annual event to raise funds for Admiral Nurses and Dementia UK. Her glamorous mum Gloria always wore red lipstick and Jules saw it as an opportunity to raise charitable funds while celebrating the age when all mothers wore red lippy, emulating film stars in their heyday. The idea was simple – pop on your red lippy, strike a pose, share your picture and donate. This simple idea raised £12,000 that first year! Even the Dementia UK Team joined in.

"She was so thrilled because she felt as though she was back as her own person again when she looked in the mirror"

Jan Burt



After Dementia Millennium Award

Friends with a personal experience of dementia supported the Charity to gain this Award

In the early 2000s the voices of family carers were finally beginning to be heard. The 'After Dementia Millennium Award' was a real opportunity to build on this.

The Awards scheme was run by the Alzheimer's Society in partnership with Alzheimer Scotland and Carers UK between 2001 and 2004. It was funded by the Millennium Commission. Its aim was to enable carers who had looked after a loved one with dementia to rebuild their lives.

Andrea Gover, Hilary Leslie and Susan Shear, friends of mine, had agreed to head an application for a grant under the Millennium Awards Scheme. All three had been involved in the care of a parent with dementia and had received support and advice from the Charity **for dementia**. The grant received was used to set up a 'Carers Network'. The grant included funding for two carers' newsletters, two workshops and a series of informal meetings, but this had to be used within a relatively tight time frame.

Sue Heiser, who I had previously met when she was working on the 'Care Must Be There' report, joined us to run the two workshops identified in the Millennium Awards Scheme proposal – one in Maidstone in Kent, the other in London, which were extremely productive. Sue was at the time a freelance trainer/facilitator, and offered those attending an insight into what individual carers could achieve. This led to an increase in volunteers for training in speaking to the media, joining a recruitment panel, partaking in interviews and dealing with the press. This was all part of the Charity's drive to encourage carer participation in order that their voices be heard.

"We were real people caring and they knew that we had been through similar situations"

Andrea Gover



We worked swiftly since the funding had to be spent within a year and we completed all its activities successfully, with a small underspend at the end. In August 2003, rather than return the balance remaining, we organised a 'Carers Network' day out on a boat named 'William B' sailing down the Thames, for seventy family carers, some accompanied by people with dementia, and Admiral Nurses. In order to keep within the guidelines of our application, the river trip became an informal launch of the Supporters Network.

In order to mark the end of the Awards scheme, Andrea and Hilary attended a special lunch held at the Café Royal in London's Regent Street. Andrea was both surprised and delighted to discover her photograph taken with the winner of the raffle on our river trip had been used for the front cover of the Awards programme. HRH Princess Alexandra, Patron of the Alzheimer's Society, visited the exhibition of awards projects before attending the celebration Lunch.

Developing a Carers' Network

It had always been my intention to develop a more structured way for the Charity to connect with families supported by Admiral Nurses. Andrea, Hilary and Susan were included in a small working group to establish a plan to form a committee and grow the Network.

During 2002 five introductory meetings were held in partnership with local Admiral Nurses in Chatham, Maidstone, Kensington, Haringey and New Malden. Our introduction to carers was still reliant on the few established Admiral Nurse teams. During 2003/2004 further workshops were held including a very well attended meeting in Manchester in the summer of 2004.

The added support of our specialist nurses at these meetings proved invaluable. It also helped to establish the connection between the Nurses and the Charity.

Andrea and I travelled to various parts of the country to increase the Network's membership.

Meeting at Hartwell House – 16 and 17 January 2005

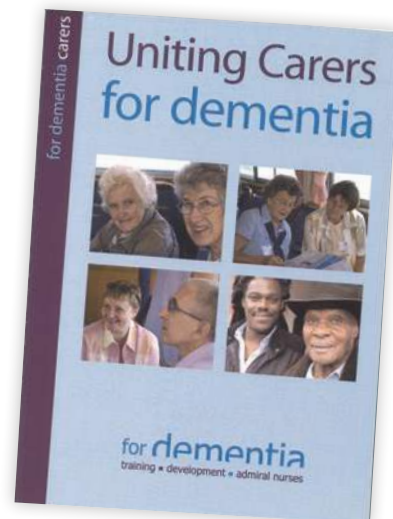
The Charity held a 'think tank' Away Day inviting several new carers who had shown interest. Many joined us at Hartwell House in Aylesbury, Buckinghamshire.

I particularly recall this event since as representatives of the Charity, Barbara Stephens and myself were allocated the smallest single back rooms high up in the eaves of the hotel. We were pleased to discover that the carers who joined us had been given superbly decorated double rooms, some even had four poster beds! Somewhat amused we never begrudged them their enjoyment during the stay.

Key decisions were made, a new name for the Network was agreed and '*Uniting Carers for Dementia*' was duly formed. Issues around membership, purpose, objectives and mission were discussed. Timing for an official launch of the Network was agreed.

The Launch of Uniting Carers for Dementia

Uniting Carers for Dementia was officially launched at the Birmingham Botanical Gardens on Wednesday 10 August 2005. It was the result of two years' work undertaken by a dedicated group of carers intent on promoting better public and professional understanding of dementia led by Andrea Gover. The key objective was to raise the profile of carers' issues and to empower carers to speak about their own experiences as well as actively promote the work of Admiral Nurses.



The Charity was most grateful for the support of Shire Pharmaceuticals who very kindly sponsored the Carers' Network meetings held during 2005 as well as the official Launch event of *Uniting Carers for Dementia*. It was never easy for such a small, relatively unknown charity to secure such helpful sponsorship.

It proved to be a very successful day attended by 130 family carers from many parts of the country. After the presentations and lunch there was plenty of time for people to mingle and speak informally to Admiral Nurses, representatives from **for dementia** and other carers. Among those we met in Birmingham were Mick Scully and Rosemary Clarke who both joined the Uniting Carers committee.

"It comes down to demonstrating the impact of what an Admiral Nurse can do and listening to the difference you've made to that family member and the family as a whole. Listening to a carer saying this makes a real difference"

Paula Smith



Away day at Sopwell House – 29–30 March 2006

After the official launch of Uniting Carers we held a second Away Day at Sopwell House, Hertfordshire in March 2006. We experienced another productive day with useful discussions about the role of the proposed Co-ordinator, who would be the Network's main contact at the Charity. Once funding was identified, Joy Watkins was appointed as the Network's Resource Co-ordinator in April 2007.

Meeting at Hatfield House – 15 August 2007

Our gathering at Hatfield House on 15 August 2007 offered the opportunity to officially introduce Joy and enable her to meet current network members. There was a full programme which once again included the personal experiences of family carers.



One of many lovely stories to emerge from establishing the Network was meeting Pat Mills, who attended the meeting in 2007 with her mother, the carer for her father. They joined the Network and a little later Pat joined the Charity as an official member of the **for dementia** staff team, working as an Administrator with Admiral Nurses – and she is still there!

The role of members of Uniting Carers would not be considered dissimilar to the current Volunteer Ambassadors who today have increased responsibilities in support of the Charity. Andrea Gover, and I spent much of this time travelling to different parts of the country holding meetings and workshops to explain the work of the Charity, Admiral Nursing and the Carers' Network.

Over the years Uniting Carers for Dementia engaged carers and former carers in an extensive range of activities. I became Chair of this committee, after Andrea, when I retired from the Board of Trustees in 2005. Later Rosemary Clarke took over the Chair of Uniting Carers, with Val Green as Vice Chair. Jean Tottie and Brian Hills then undertook these roles. Other key people actively involved in the beginning of Uniting Carers included: David Royle, John Moore, Pam Millard, John Roussel, Baktash Manavi and Mick Sculley.



Music for Life

'Music for Life' was founded by Linda Rose in 1993 and developed with a team of professional musicians in association with Jewish Care. 'Music for Life' aims to enhance the quality of life of people living with dementia by using music to optimise their potential for self-expression and communication.

Dementia facilitators support the learning of care staff to enable them to develop their emotional awareness and interpersonal skills, creating opportunities for deeper connection with the people with dementia they care for.

The training department of Dementia UK worked collaboratively with Wigmore Hall to deliver 'Music for Life' programmes in residential care and nursing homes (mostly in Westminster) from 2009 until 2013. Dementia UK trainers, Dave Bell, Aubrey Maasdorp, Rachel Thompson and Julia Burton-Jones delivered staff and musician development sessions in support of 'Music for Life' over the four-year period of Dementia UK's involvement. The partnership with Wigmore Hall was overseen and facilitated by Emma Hewat.

HRH Princess Alexandra is Royal Patron of 'Music for Life'. Liz Anderson (trustee) and John Suchet were patrons of 'Music for Life' on behalf of Dementia UK for the period of the Charity's involvement. The Charity's association with 'Music for Life' ended when the Charity re-aligned its strategy in 2013 and the training department closed.

Since the benefits of music and singing for people with dementia have become more widely recognised the number of 'Dementia' choirs has grown. These regular sessions also provide a welcome opportunity for family carers to meet and enjoy the company of other carers. As early as the 1980s Monica Greenwood recognised the benefits of music and had the foresight to organise regular singing sessions with an old time music hall singer in her unique ward at St Pancras Hospital. She recalls: *"These old ladies and some men would join in with the chorus – they couldn't speak but they could sing – they knew the words – it made me cry it was so moving."*

I attended an event with Barbara Stephens, trustee Liz Anderson and others from Dementia UK to celebrate this project at the Wigmore Hall, in the presence of HRH Princess Alexandra. The Charity was always interested in any projects which benefitted those living with dementia and their carers so it was not unprecedented that it joined other charities to support this project.

Liz Anderson – Trustee 2006–2012



Liz was Arts Editor at the Spectator when she joined the Charity, having had personal experience of Admiral Nurses when caring for her partner, well-known writer and broadcaster Bernard

Levin. After his assessment by Monica Greenwood, Bernard attended a day centre and it was there that Liz met Dave Bell and was introduced to Admiral Nurses. Dave offered both practical and emotional support on a regular basis.

Liz learnt more about the Charity from her friend and then Chair Vicky Wilson and in 2006 she was invited to join the Board of Trustees. Liz was interviewed by Sacha Bonsor for the Times in 2007 when the Admiral Nursing DIRECT Helpline was launched, creating increased publicity for the Charity. Liz's direct experience proved very helpful to the Board as she explains: *"Only someone who has known an Admiral Nurse can appreciate what they do for a carer and how lost a carer can feel without support. Knowing Dave was there for me kept me sane. I owe him and Admiral Nurses so much"*

"Admiral Nurses are a lifeline to a carer's sanity"

Liz Anderson



Changing Course

Staying Aboard

Apart from those already mentioned, recognition should be given to those who voluntarily offered their time, energy and expertise during this critical period of the Charity's development. These were turbulent years, but three key people who remained aboard worked incredibly hard to keep the Charity afloat. Their continued support during some of the most perilous times is acknowledged.

Ann Windiate – Chair 2009-2012

Ann became Chair of the Board in January 2009. She had brought a wealth of knowledge to the Charity since she joined the Board in 1996, while Director of Social Services in Westminster. Ann then became Chief Executive of Riverside Mental Health Trust, where some of the first Admiral Nurse teams were established, before moving to Medway Council in Kent as Director of Health and Community Services. Ann succeeded Victoria Wilson who stood down after a successful three-year tenure.



John Steele Trustee 2006 Honorary Treasurer 2009-2012

John Steele retired from the Home Office after a career spent in the criminal justice system. He joined the Board earlier in 2006



becoming Hon Treasurer in 2009 taking over from John Libson. Mike Stansfield took on the role from 2012 until 2014.

Rosemary Clarke (Vice Chair) Interim Chair 2012

On Ann Windiate's retirement, Vice Chair Rosemary Clarke became Chair on an interim basis whilst the Charity actively recruited for someone outside the Board to take on the role. Rosemary had originally been introduced to the Charity in 2005 at the launch of Uniting Carers in Birmingham, having heard about the Charity when caring for her mother. She had worked closely with Professor David Jolley and Kate Read supporting dementia care and Admiral Nurse developments in the West Midlands. Rosemary retired from the Board later the same year after the appointment of the new Chair.



After 14 years Barbara Stephens leaves the Charity



Barbara Stephens stood down as Chief Executive in 2013, coinciding with the Board's strategic decision to align the Charity exclusively with Admiral Nurses. Barbara felt strongly that the helm should

be taken by an effective nurse leader who could build and strengthen the evidence base demonstrating the value of Admiral Nursing as a family-centred model, and embed Admiral Nursing as a discipline into commissioning frameworks in health and social care nationally.

Barbara led the Charity through many changes. Her creative approach generated productive collaborations with NHS Trusts, social care providers, community and third sector organisations and people living with dementia and family carers. Always at the heart of her work was the key goal: to improve the quality of life for people affected by all forms of dementia. She had a strong belief that the key to change was to understand the viewpoints of people living with dementia and to work in partnership with families and carers.

Barbara's achievements included:

- Designing a casework approach for Admiral Nurses (widely recognised as a best practice model) underpinned by an electronic case recording system used by Admiral Nurses across the UK.
- Leading the first wave regional development of Admiral Nurses in the North West.
- Masterminding the second regional wave in the West Midlands and a raft of new team developments elsewhere in the country, including Kent, Yorkshire, Norfolk, North East London, Essex, Hampshire and Kent.
- Creating partnerships with charitable and independent care organisations, leading to the establishment of Admiral Nurse posts based within community settings and care homes.
- Establishing Admiral Nursing DIRECT, the UK's only nurse-led dementia helpline.
- Leading the Charity through two rebrands, notably in 2010 when the name 'Dementia UK' was adopted.
- Creating links with universities, establishing senior Admiral Nurse roles, encouraging Admiral Nurses to be research-active and undertake higher-level degrees.

Barbara supported all fundraising activities, enabled the growth and diversification of the training department, and was pivotal to the formation of Uniting Carers for Dementia. Her perseverance and resilience, often in very challenging circumstances, were notable strengths. Robust foundations were established during her 14 years of tenure in the Chief Executive role. The scene was set for the impressive endeavours that have followed under the new regime.



A new regime takes the helm

David Croisdale-Appleby OBE becomes Chair in July 2013

Under David's leadership the Board made some difficult strategic decisions to consolidate resources around the single focus of Admiral Nurses. The Board then agreed to disestablish Uniting Carers and the Training Programme. These were exceptionally difficult decisions for the trustees, myself included. Although I accepted and fully understood the sound reasoning behind the proposals, like others, I found the decisions hard, but refocussing on the Charity's original purpose to support and develop the number of Admiral Nurses was without doubt the sensible way forward. I supported the Board's decision.



"Early in 2013 I was invited by the trustees to become its executive chairman, to create a new strategy for the organisation refocussing on its core purpose, the provision of the Admiral Nurse Service to carers and the families of those with dementia, both in-person and through the helpline. This necessitated creating a new business model which would facilitate achieving the twin strategic goals of the highest possible quality of service and a very great rate of expansion of our nurse numbers.

I was able to appoint an inspirational nurse, Dr Hilda Hayo, as the CEO, and together we recruited new trustees and formed a new executive team including the superbly-talented fundraising director, Martin Bishop.

The Charity has grown phenomenally, over tenfold since 2013, and today stands at c.£20million income and 450 Admiral Nurses, along with a fully staffed helpline. We have a highly talented Board and an exceptional Executive, so we are well set for the next ten years of service and growth."

Professor David Croisdale-Appleby OBE Chair – Dementia UK

Hilda Hayo appointed to the dual role of Chief Executive and Chief Admiral Nurse in September 2013



"In 2013 I was appointed as Chief Admiral Nurse and CEO of Dementia UK. The Charity was doing great things for families impacted by dementia but the scale needed to be developed further in order that more families could benefit from the expertise and compassionate care Admiral Nurses are so renowned for.

When I commenced with the Charity the trustees and I devised a three-year strategy which aimed to increase the number of Admiral Nurses, and increase the funds coming in to attract high

calibre staff to aid in the development of the Charity. This and subsequent strategies were successful and as a result the Charity now has over 450 Admiral Nurses who are developed and supported by Dementia UK. In addition, we now have a seven day a week Admiral Nurse Helpline and Clinics service to meet the needs of families impacted by dementia who do not have a local Admiral Nurse Service. This enables us to reach many more people who need the expertise of dementia specialist Admiral Nurses.

The trustees and Dementia UK team are committed to the continual development of the services and support we provide, so that all families can access the specialist advice, support and understanding whenever it is needed."

Dr Hilda Hayo – Chief Nurse/CEO – Dementia UK

Martin Bishop appointed Director of Fundraising, Marketing and Communications in August 2014

“There have been huge changes since I arrived in August 2014. At that time there were nine people in the Fundraising and Communications team, and the Charity’s income was £2.3 million.



One of the first things I knew we needed to do was launch a new brand identity – that linked Dementia UK and Admiral Nursing – and a new website. Trustees approved the budget to do just that, and we began in early 2015. They were big projects, with Jane heavily involved on the brand side; we launched both the new brand and the new website in early November 2015. In many ways we have never looked back since.

We had really good growth in fundraising, marketing and communications activity over the next few years; but faced with the challenges of the Covid-19 pandemic we expected a significant

hit to our income. Although in many areas income initially fell, we bounced back through support from individuals, companies and trusts. But when the new Head of Community and Events introduced a virtual events model, and launched a Dog Walking Challenge, our income exploded. We ended the year in March 2021 with an income of £15 million.

As I write I know that income has now hit c.£19.4 million and we have a team of 73 and growing across the Fundraising and Engagement directorate; supported by over 100 Volunteer Ambassadors. The Engagement part of the team name covers Marketing and Communications, but also our relatively new Policy, Campaigns and Public Affairs team; an area we are looking to expand as we implement a ten-year influencing strategy to transform dementia care in the UK.

It’s been a very good, very enjoyable and very satisfying nine years.”

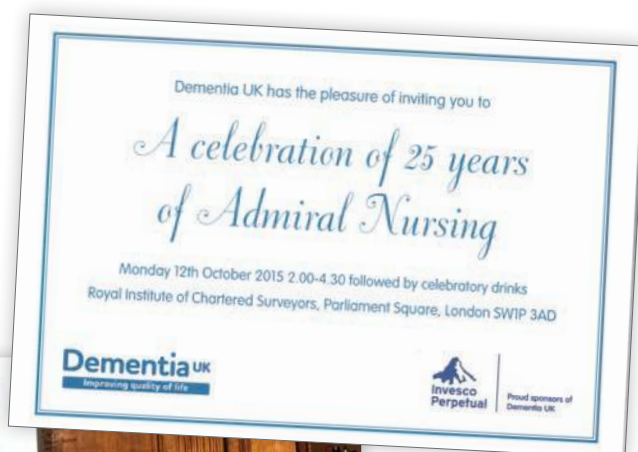
Martin Bishop – Director of Fundraising and Engagement – Dementia UK

A new identity for Dementia UK

An extensive rebranding exercise was undertaken during 2014/15. As my final key role as a trustee I worked with the newly appointed then Director of Fundraising, Marketing and Communications, Martin Bishop, who had the main responsibility of creating a new image for the Charity. During the summer of 2015 we worked closely with the team from creative marketing agency Arthur London, involving many different stakeholders. The challenge once again was to link both brands, Admiral Nurses and the Charity. Although I’m not entirely convinced this was achieved, the final choice was one preferred by the majority and perfectly acceptable to others. However, this has clearly proved very successful.



I retired from the Board in October 2015 after 20 astonishing years. Marking my official retirement, the Chair David Croisdale-Appleby kindly invited me to become Dementia UK's Honorary President. This was announced at the event held on 12 October 2015 to celebrate the 25th Anniversary of Admiral Nursing.



Sailing on

Having outgrown offices yet again, in 2018 the Charity was quite literally on the move once more to their current base at No 1 Aldgate. I was delighted to be invited to the official opening of the new offices. I joined Chair David Croisdale-Appleby, who performed the ribbon cutting ceremony, whilst I was given the traditional task of slicing the Dementia UK cake.

Looking around it seemed so far from that tiny back office in Waterloo Place. No one can be sure how long the Charity will remain in Aldgate with the introduction of hybrid working but it was reassuring to see that the organisation was now well established and ready to move forward with enthusiastic new people leading the way.

With leadership comes the responsibility to make important and difficult decisions, the hardest one for me was choosing the right moment to finally let go and move on. The Charity had great potential but the right people were needed to take it forward. I believe the evidence speaks for itself.

I am extremely grateful to the Board of Trustees who gave me the opportunity to continue my close relationship with the Charity and to those working at Dementia UK who have kept me so well informed enabling me to fulfil my obligation as Honorary President.



The next challenge!

The Admiral Nurse Family

Admiral Nurses - what they really think

"I think it's pretty amazing that so many of the nurses are still around either directly or indirectly. That's a real success story – people move around so much these days, to have people there after 20/25 years is pretty phenomenal!"

Huw Meredith



"It's been part of my life for nearly 30 years"

Admiral Nurse Alison Coignard reflects on her recent retirement:

"I've always felt very privileged to be an

Admiral Nurse, right from the times of the very few, to now when there are over 400 and many more to come. It's been an incredible journey from its innovative infancy to a more mature and equally sought-after service but by many more people. Admiral Nurses have held on to the passion for the work they do, which those who benefit from it so appreciate.

One of the strengths of Dementia UK has been their absolute belief and support of Admiral Nurses through the years, nurturing us to develop the model, which stems from the work we did in the Charity's earliest days. Its success and the reason for Jane Jason's words 'Once an Admiral Nurse always an Admiral Nurse' is that we all believed in it.

I was fortunate to meet the family and to witness the early meetings where formation of this new professional, who would support families of people with dementia, took place. It made absolute sense to me. Once adopted by the NHS, I applied and never looked back, it's been part of my life for almost 30 years."

"They capture what the essence of nursing is, it is knowledge backed up by caring"

Alison Soliman

"They're a navigator really and they take it in turns taking the helm with the carers because they don't need to do it all the time. That's why I like the analogy of the sailor and the boat, sometimes you do have to help someone ride the storm and other times you might navigate around it. Hopefully the more storms we navigate the better"

Karen Harrison Dening

"I used to say Admiral Nurses were like a professional friend. They see you as a friend but most importantly they recognise that there are professional boundaries"

Susan Ashcroft-Simpson



“Admiral Nursing is not rocket science”

**Consultant
Admiral Nurse
Pam Kehoe
explains:**

“I believe that Admiral Nursing is not rocket science, nor should it be, we are working alongside families with thoughts, feelings and emotions. However, that is not to say that it is not a skilled and specialist role.

The best Admiral Nurses recognise that we are making a meaningful difference to the lives of families. We have the privilege to enter when they are often at their most vulnerable. We do so with empathy, warmth and genuineness (and perhaps the ability to think outside the box too). We impart knowledge at a pace that we know is right for the unique individual, because we truly understand that ‘no one size fits all’ for families affected by dementia. “One of my families once said that I was like a stick of rock.... They said, if they cut me in half they would find ‘Admiral Nurse’ running right through me – what a great compliment!”



Kerry Lyons – Admiral Nurse in an acute hospital setting

“I have seen the challenges that

families face. I wanted to be in a role where I could make these situations better for families living with dementia.”

Kerry was an Admiral Nurse in an acute hospital setting when we met four years ago. She has recently been appointed the first Consultant Admiral Nurse for Frailty, supporting families living with frailty and dementia.

Kerry, the winner of two prestigious national awards in 2020, says *“It was never about personally winning, it was about the opportunity to grow Admiral Nursing. I feel truly privileged to be an Admiral Nurse, we are welcomed into someone’s life, often at times of severe crisis. The trust we are given is amazing. I have first-hand experience of supporting a loved one with dementia, therefore I recognise the value of the expert clinical, practical and emotional support Admiral Nurses offer families living with dementia.”*

Kerry believes strongly in Admiral Nurses in an acute setting, stating *“I’m sold on an Admiral Nurse within a Hospital. I can absolutely see the benefits to my families, to my carers, to the organisation from an outcomes point of view.”*



Jeni Bell – The first Admiral Nurse in a hospital setting – looks back on her career

Jeni, who set up the first Service in a hospital setting in Southampton says:

“It was 2009, in the good old days! We had the ability to have fun and the opportunity to connect and get to know each other. We would learn from each other and get support from each other, we’d share our different experiences and difficulties. The old rearguard hardcore of Admiral Nursing learnt on the job, we went into nursing because we wanted to care for people.”



Admiral Nurses - we are a family



“Jane always says once an Admiral Nurse always an Admiral Nurse. I left Admiral Nursing 15 years ago and I’ve never gone back but I still feel like an Admiral Nurse”

Lynda McNab

“You ask all of us Admiral Nurses who have left the thing we hold on to most is that we were part of that, are still part of it and we still want to be part of it”

Tony Braker



The unique ‘Admiral Nurse family’ was created as they fought to establish a strong foothold in a surprisingly hostile world. In spite of tough opposition, they succeeded collaboratively in establishing the remarkable service for carers which exists today. Mark Lawton remarks *“There’s a knowledge, an understanding and empathy, there’s a personality trait I can’t quite put my finger on that screams ‘Admiral Nurse’”*.

A new generation, a new ‘family’ of Nurses is now growing up, closely following the example of their predecessors. Most Nurses seem to stay forever, but even when they leave or retire the experience of having been an Admiral Nurse stays with them always.



To acknowledge the length of service, an internal award was created for those who had worked as Admiral Nurses for 20 years or more. I was privileged to be asked to present some of the first certificates.

It has also been my privilege to meet many dedicated individuals who have been a part of the journey over the past thirty years, far too many to mention in person. The many trainers and those who have worked behind the scenes, below decks, to make the Charity what it is today should be acknowledged for the valuable contribution they have all made.

“Once you become an Admiral Nurse it’s like joining a family”

Madeline Armstrong

“What was really important to keep us going was that sense of family with Dementia UK”

Helen Springthorpe



“It’s about the way people looked after each other and that’s what families do”

Rachel Thompson



From Jane to the Admiral Nurses

Thanks for the memories

I certainly have so many wonderful memories, the ones which really stand out are; karaoke, drinks after work at the pub, dinners at El Parador; having the best fun in the worst hotels where the late night 'Hardcore' group was formed; the one and only Dave conducting a midnight sing song while Debbie served drinks from the hotel bar. 'Admiral Nurses Got Talent' named after the television show also springs to mind. At the 2009 Forum at Canary Wharf Admiral Nurses performing as Abba were only surpassed by the winning duo Dave and Madeline singing "*I got you Babe*"!

"Gosh! 30 Years of Admiral Nursing – where has the time gone? We were all so young then. There are so many memories and stories"

Penny Hibberd

Retired Consultant Admiral Nurse,
now living in New Zealand

"That's one thing
about nurses –
they love a party!"

Peter Carter





From the Admiral Nurses to Jane

Annelene Tearle (Project Research Assistant) talking to the Nurses

As part of the research for this book Jane and I met with some of the very first Admiral Nurses – some of ‘The Originals’. At the end of our interview, I took the opportunity of asking the Nurses about their relationship with, and impression of, Jane over the years. They all have lovely fond memories.

To Jane

At the end of the 1980s, a very small, select group of people including Jane met on a regular basis to develop a role which would support family carers of people with dementia. To a nurse who had worked with people with dementia the need to support families made perfect sense, and the role of Admiral Nurse became one to which many nurses working in the field of dementia would aspire.

In those early days, a new Admiral Nurse would meet the Levy family a few days after beginning in the role, at the offices of the Joseph Levy Foundation. This first meeting felt like being welcomed into a new family, such was their warmth, enthusiasm and absolute belief in this innovative approach and in us as nurses. It emanated from the family in those early days and continues amongst the ‘wider family’, the Charity, today.

“How many people in Jane’s position would go to the events, the Development Days. She’s been at everything – she’s there”

“Jane gets the professionalism of the nursing that we do”

“She’s kept her energy going all the way through”

“I think Jane is the Charity – you can’t separate the Charity from Jane”

“Yes, she steered it all the way”

Subsequent years saw a gradual increase in the number of Admiral Nurses. To use a sailing analogy, Jane was always at the helm, steering the Admiral Nurse ship with an unfailing belief in us. She was at all the meetings, practice development days and conferences – a constant, enthusiastic figurehead.

As Admiral Nurses, Jane has made us feel like the best nurses in the world – privileged and looked after. The fact we felt that way and happily poured ourselves into work, continually studying and developing as dementia specialist nurses, saw the role of the Admiral Nurse gradually becoming what it is today. In fact, we were so happy, those of us who left would often find their way back again and as Jane would joke: “Once an Admiral Nurse, always an Admiral Nurse.”

It has been an honour and a privilege to be able to represent the Charity and the work of Admiral Nurses. We were given opportunities we would not normally have had. We were invited to take part in many events, getting out there and talking about our work, at charity fundraising events, presenting at conferences, meeting and speaking to people we would never ordinarily have had a chance of meeting.

It wasn’t all plain-sailing but Jane built the strong foundations upon which Dementia UK, and the Admiral Nurse Service we have today, have grown. Its success and strength is testament to Jane as a person – her vision, which never faltered and felt so right to us Admiral Nurses, her enthusiasm, tenacity and her ability to bring us with her on her journey.

This story wouldn't be complete if Jane's wonderful sense of fun weren't mentioned. When the working day – conferences, charity fundraising events and so on – was done, she would lead us into 'fun and frolics' and then always made sure we got home safely – she still does! It's not for nothing some of us think of her as our big sister.

Jane, from all of us 'Originals' and the Admiral Nurses of today, who are carrying this lamp into the future, all the families helped over the years, the dementia training team who took the message out to care homes and those who continually work behind the scenes to keep the Charity running – thank you for your vision, your leadership and never giving up. From those early beginnings with just a few Admiral Nurses, through to the hundreds of Admiral Nurses of today, your legacy is truly awe-inspiring and the award of OBE, richly deserved. Ninot and Joseph Levy (Admiral Joe) would be justly proud of you – you are the Charity, Dementia UK!

Thank you Jane.

“And how many Chairs would actually know the people that work for them”

“She's seen the highs and lows. We were all learning, but it always felt like Jane believed in us”

“That's where we get our energy from as well – she's just so passionate”

“And we can really have a joke with her”



Dementia today

The landscape has changed significantly since the Dementia Relief Trust was established in the 1990s, when there was little recognition of the widespread prevalence of dementia and its impact on families. People with dementia were largely invisible. Family carers carried the majority of the responsibility, although the enormity of the task was unrecognised the consequences for their physical and mental health were significant.

As carers have spoken out more, and people with dementia have been accepted for the people they are, rather than being defined by their dementia, public attitudes have changed. There is greater knowledge about dementia nowadays and a more sensitive appreciation of what it might be like to live with this condition.

The dementia strategy launched in 2009 was game-changing. For the first time, dementia was finally given political priority. The drive to improve diagnosis and treatment led to investment in developing memory clinics, and the dangers of over-prescribing anti-psychotic medications were investigated and publicised.

Dementia Strategy

The first national dementia strategy for England was published in February 2009 by the Department of Health. Calling for improvements in diagnosis rates and post diagnostic support for people living with dementia, investment in workforce development and initiatives to raise awareness and promote better understanding of dementia in the wider community, the strategy changed the face of dementia care and gave the condition unprecedented visibility.

The dementia strategy identified 17 key objectives which were designed to bring about significant improvements in the quality of services provided to people with dementia and promote a greater understanding of the causes and consequences of dementia.

After the general election in 2010, the strategy was reinvigorated by Prime Minister David Cameron, who launched a national challenge to fight dementia in 2012. Then in 2015, the 'Prime Minister's Challenge on Dementia 2020' was published, setting out ambitious plans to improve the quality of care for people living with dementia, create dementia friendly communities, overcome barriers to engaging with seldom heard groups and increase investment in research.

Fast forward to 2023, dementia is now included along with cancer, cardiovascular diseases and musculoskeletal conditions in a proposed 'Major Conditions Strategy' designed to promote healthy lifestyles and delay the incidence of conditions that are detrimental to the health and quality of life of older people.

The Charity Today

Dr Karen Harrison Dening, Dementia UK's Head of Research and Publications, describes the importance of developing an evidence base for Admiral Nursing and research priorities for Dementia UK

As the commissioning agenda changes, and the development of new Admiral Nursing Services must rely on having its own evidence base, never has it been more important for Dementia UK and Admiral Nursing to develop its own research priorities. It was in 2014 that I started a project to develop evaluation mindedness in Admiral Nurses – GEANS (Getting Evidence into Admiral Nursing Services). GEANS was designed to build the skills and capability of Admiral Nurses to evaluate their practice and services and integrate data collection and service improvement culture into their daily work. There were several people who joined me including Zena Aldridge. She had completed an evaluation of her new Admiral Nursing Service in Norfolk which gave us a massive head start using evaluation methodology. This work started the process of systematically collecting data on what Admiral Nurses do, to whom and the outcomes for families affected by dementia. A Service Evaluation Team was created to progress this work and to aggregate data from all Admiral Nurse Services.

Several Admiral Nurses undertook advanced degrees. Dr Julia Botsford, Dr Penny Hibberd and myself all benefited from the support of Dementia UK to do this and successfully gained PhDs. Developing research mindedness in the body of Admiral Nurses has always been an aim, from the early days of the first competency framework through to the present day. The Research team and many Admiral Nurses have become independent researchers, collaborators, co-applicants, expert advisors and members of research management committees for many significant research studies both in the UK and globally. Dementia UK and Admiral Nursing are now confidently 'at the table' of dementia care research. 2023 will see the launch of Dementia UK's first research strategy for Admiral Nursing that sets out the top five priorities for the next three to five years.

Dementia UK Chief Executive Hilda Hayo sets out the Charity's structure in 2023:

Growth and change of staff teams

Admiral Nurse Academy Team: This was developed to support Admiral Nurse professional and practice development. As the numbers of Admiral Nurses have increased over time the support offered has increased and includes:

- practice action learning sets
- a dedicated learning and development site
- support of new services for the first six months
- development of a pre Admiral Nurse Module
- an accelerated learning programme for nurses to become Admiral Nurses
- lived experience coordinator
- inductions of new Admiral Nurses
- online Admiral Nurse Forum
- online Summer School

Business Development Team: This team strategically develops hosted and part funded Admiral Nurse posts across the UK. Once the Admiral Nurse/team is in place they account manage the service in order to retain the post, develop the post further and work on adding extra nurses to the service.

Insights and Evaluation Team: This team evaluates the effectiveness of Admiral Nurse provision and prepares reports that can be disseminated to external and internal audiences.

Research and Publications Team: This team takes what has been produced by the I&E team and prepares this for publication in books, research papers, conferences, articles etc. In addition, they play an active role on external research projects with other organisations

Consultant Admiral Nurses: These nurses have a small clinical caseload, are engaged in evaluation and research, development of staff and have a national profile. So far we have Consultant Admiral Nurses for:

- Lewy body dementia (came into post Jan 2020)
- Frailty (came into post Jan 2023)
- Young Onset Dementia (came into post May 2022)
- Sports and Dementia (came into post May 2023)

Admiral Nurse Clinics Team: We are aiming to develop more over the next few years. These teams are relatively new and were introduced following the success of other Admiral Nurse Clinic models that we delivered on an ad hoc basis. They are currently a Monday to Friday 9am-5pm service where families impacted by dementia can book an appointment either online via zoom or by phone. We are aiming to increase the opening times in the next year to include evening and weekend clinics.

Admiral Nurse Dementia Helpline Team: The opening time of the Helpline has been extended to seven days per week with weekdays opening times of 9am-9pm and weekend 9am-5pm. The numbers of nurses working on the Helpline has increased to 14 working on day shifts in the weekdays, five in the evening and weekends.

Young Onset Dementia: After the merger with Young Dementia UK in November 2020 our charity became more focussed on services and support for families impacted by young onset dementia. We have developed specific resources for families and some specialist young onset dementia posts in local communities.

Current figures: (Figures quoted are for 2022)

Admiral Nurse Helpline: 33,421 contacts

Admiral Nurse Clinics: 2,870 appointments

Supporting Dementia UK

Donate to Dementia UK and help ensure there's a specialist dementia nurse for every family that needs one.

Every three minutes someone in the UK develops dementia: a progressive and complex condition that can be devastating for the whole family. Too often, people are left to cope alone with ever-changing and relentless challenges. Families often have to take on caring responsibilities that push them to their physical, emotional and financial limits. Struggling to know where to turn, they are left feeling exhausted, overwhelmed and alone.

That's where our specialist dementia nurses — known as Admiral Nurses — come in.

As experts in the condition, their tailored, life-changing support helps families through the fear and confusion of dementia. From sharing practical tips for caring, to offering compassionate emotional support and helping families plan for the future, they are there when people need them most.

Every day, Admiral Nurses help families up and down the country to have the best life possible for as long as possible. Whether it's via our Helpline, clinics or in the community, our nurses give families the much-needed space to talk to someone who understands. It's why so many families describe Admiral Nurses as a lifeline.

Yet there are still thousands of families who desperately need our help – and with dementia now the leading cause of death in the UK, your generosity is more important than ever. We urgently need your donation to make sure everyone facing dementia has the tailored support of a specialist nurse.

Please donate today and help make sure that no one has to face dementia alone.



You can make a donation by scanning the QR code below, or by visiting our website at

www.dementiauk.org/get-involved/donate/



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Sandford Springs Golf Club: Cover of the Golfing Gourmet book

Lord Snowdon Estate: Photo of elderly gentleman featured in the exhibition and promotional literature for the launch of the Dementia Relief Trust

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“Practice does not become advanced simply because a nurse acquires a degree or completes a certain course. Advanced practice is a way of using skills and knowledge holistically to the highest standards.”

Alison Soliman



“I tell the story of Admiral Joe and how Admiral Nurses got their name; every charity should always remember its roots and foundations and its history”

Mike Phillips