

Getting Admiral Nurses for the people of Bucks.

Presentation to

Dementia Action for Marlow and Bucks Older People Action Group

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I'd like to begin by thanking you for the invitation to meet with you today, and particularly to thank Dementia Action for Marlow for the wonderful work it has done in bringing to the attention of the public and to commissioners of dementia services the need for an Admiral Nurse Service to serve the people of Bucks.

Introduction.

In my talk today I'm going to do 8 things:

- 1. Tell you just a little about dementia
- 2. Explain the scale of the issue
- 3. A brief history of DementiaUK and Admiral Nurses
- 4. Share with you the impact of dementia
- 5. Explain my organisation (Dementia UK)'s role in providing support to people who have dementia, but especially to their family carers, and the current situation in September 2022
- 6. The evidence of the Effectiveness of our Admiral Nurses
- 7. R*****'s story
- 8. How together we are getting an Admiral Nurse service for Buckinghamshire and local area.

1. What is dementia, and what's the difference between Dementia and Alzheimer's?

Dementia is the umbrella term for a collection of symptoms that may include problems with: memory loss, thinking speed, mental agility, language dexterity, understanding and judgement.

Dementia is caused when the brain is affected by specific diseases or conditions. Dementia is progressive, so the symptoms will get worse over time - how quickly, though, will vary from person to person, and on which form of dementia they have.

There are over 100 different types of dementia, with 4 frequently-occurring types:

- Vascular dementia,
- Alzheimer's
- Fronto-temporal dementia, and
- Dementia with Lewy bodies,

Some people get diagnosed as having mixed dementia; this is when the person has symptoms of more than one type of dementia.

2. The scale of the issue?

As I am sure you know, dementia is a growing problem which is affecting more and more people: there are currently some 900,000 people living with the condition in the UK, and this is expected to increase to over 1.1 million by 2025, and 2 million by 2050.

Additionally:

- One in three people over the age of 65 will develop dementia. And as life expectancy increases, more and more people will be affected as the incidence of the disease increases rapidly for those over 80.
- Dementia is the leading cause of death in the UK, having sadly now overtaken cancer and heart disease. It is also by far the most feared disease.
- More than 5,500 people in Bucks will develop dementia this year.
- Dementia needs to be diagnosed in a specifically designed Memory Clinic, otherwise it can be misdiagnosed as delirium, age-related memory loss, or other conditions.
- And if misdiagnosed then it will develop more quickly than otherwise because the treatments we have at present to slow down the progress of the disease will not be administered. The effect on the person with dementia will be more distressing, and the burden of caring will be more burdensome on the carer and family, and less effective.
- Many GPs are still reluctant to pursue getting a diagnosis, arguing that as there is as yet no cure, why diagnose it? But this is unacceptable – we have a right to know our situation and to seek the best available treatment, and to be able to put our affairs into good order.

3. A brief history of DementiaUK and Admiral Nurses.

DementiaUK was a small charity which had been funded primarily by a family in London who had lived through the misery of trying to cope with and care for a much-loved, elderly member of their family whom the family called “Admiral Joe” because of his love of sailing.

They found that the NHS, Local Authority, District Nurses, GP Practices and others in the public sector offered little or no help. They finally found a nurse who understood what families caring for people with dementia were going through, a nurse who had a clinical understanding of the disease, because dementia is a disease, not a condition just associated with the normal process of ageing. She was able to explain to the family what was happening to Admiral Joe, explained how the disease was affecting him, why his behaviour was changing, and offered informed advice on how best to care for him.

So overwhelmed were the family with the difference to their lives as carers, and to Joe’s life, that they wanted such support to be available to other families, and set up the charity DementiaUK to bring this into effect through creating the set of clinical understanding, skills, competencies, and behaviours that were necessary to be qualified as an Admiral Nurse, so named in memory of Admiral Joe.

Nurses were employed by a third party such as an NHS Hospital, a hospice or other organisation, and DementiaUK provided the professional training and support for the nurses.

By 2013, the charity had plateaued at 86 Admiral Nurses and lost its way. It had made the mistake of offering a plethora of associated services, lost momentum and was losing money at such a rate that closure of the charity was imminent. The trustees invited me to see if the charity could be saved.

I began the restructuring of the charity, concentrating solely on the provision of Admiral Nurses and the Admiral Nurse telephone helpline, and closed all the other activities. Together with a new Chief Admiral Nurse/CEO, Dr Hilda Hayo, we recruited a new executive team and a new body of trustees.

The newly refocused charity has remained true to its primary purpose of providing Admiral Nurse support to help families live better with dementia.

The only expansions of our remit have been;

- (1) to seek to apply pressure through lobbying to gain public funding for dementia care, and
- (2) to initiate research into dementia care, not clinical research into dementia, but research but research into measuring the impact and effectiveness of our Admiral Nurse support

4. The impact of dementia on families

As many of you here today already know, there can be a devastating impact on families, carers and loved ones. They have to come to terms with irreversible and distressing changes in their closest relationships, for example their spouse, partner or parent.

In many cases, caring for someone with dementia becomes a full time role, causing them to leave behind their careers and lives, and enter a strange, frightening and disempowering world, characterised by social isolation and an overwhelming burden of caring.

Sadly too, they are likely to have much higher than normal levels of stress, and report higher levels of depression than do carers of other older people.

This is made worse by gaps in the provision of health and social care, and where you live - care is a 'post code lottery'. Some areas such as Norfolk and Kent have a whole team of Admiral Nurses providing help, advice and support to carers, others have fewer and a very few, such as Bucks, sadly have none.

At DementiaUK we are not prepared to accept this, but with the help of you and others are striving to change it.

Once we have the first and second Admiral Nurse in an area, their impact is spread like wildfire and the demand escalates and more posts follow quickly.

5. My organisation, Dementia UK's role in providing support both to people who have dementia, but especially to their family carers

Dementia UK provides specialist dementia support for families through our Admiral Nurse service. When things get challenging or difficult for people with dementia and their families, Admiral Nurses work alongside them, giving the compassionate one-to-one support, expert guidance and practical solutions that can be difficult if not impossible to find elsewhere.

They are a lifeline - helping families to live more positively with dementia in the present, and to face the challenges of tomorrow with more confidence and less fear. DementiaUK is totally responsible for the recruitment, education, training and continued professional development of all Admiral Nurses.

We receive no government or other public funding and are entirely reliant on donations, including from people who leave us gifts in their Wills.

Admiral Nurses provide the specialist support that families need to face dementia. They are all qualified and experienced mental health nurses, employed at Band 6 upwards. Families that have their support have someone truly expert and caring by their side - helping them to live more positively with dementia in the present, and to face the challenges of tomorrow with more understanding and confidence, and with much less fear.

We believe that everyone who needs the support of a specialist dementia nurse should get one, and we're working hard to increase the number of Admiral Nurses across the UK.

The Current situation in September 2022.

1. Since 2013 we have grown from 86 to over 400 Admiral Nurses, half way to the ambition we set in 2013 to reach 800 nurses.
2. Our 9am to 9pm, 365 days a year Admiral Nurse telephone helpline is available on 0800 888 6678. This is staffed exclusively by Admiral Nurses whom we employ directly, and whenever a carer calls our helpline it is answered by an experienced Admiral Nurse who will engage at length with the caller – we do NOT employ a triaging system, since we believe that every caller should receive accurate, clinically-under-pinned information.
3. Since 2014 we have grown our voluntary income from £1.8million to £17.8million.
4. We have achieved financial surpluses each and every year since 2014, all have which have been reinvested in growing the scale of the support we offer the families of those living with dementia.
5. We have made the profession of an Admiral Nurse to be recognized as the gold standard in dementia care.
6. But whilst we have some counties with a dozen or more Admiral Nurses, a few, such as Buckinghamshire, remain without any, to huge detriment of those who care for loved-ones carrying the burden of caring.
7. We have instigated new services such as Admiral Nurse Clinics in these and other areas, where two or more of our nurses will hold 2-day clinics for which 1-1 appointments are made and a general session held for others – Bucks has had a number of such Clinics.
8. Funds have been raised in Bucks for these clinics, and additionally we ourselves have set aside up to £120,000 to identify and pay for an Admiral Nurse Service in Bucks, but so far no organization has been prepared to host and employ an Admiral Nurse, despite the high level of need, high and ever-increasing. We are setting-up an Expression of Interest process in early October to find an appropriate host or hosts.

6. The Evidence of effectiveness of our Admiral Nurses

Through our research on their impact, we are able to tell a compelling story. For example, research clearly shows that support from an Admiral Nurse: Improved outcomes for **families** by:

- lowered depression and anxiety for those in the caring role
- giving the information and confidence to seek information and support
- improved wellbeing and quality of life for those with Dementia

For the health and care system as a whole, the employment of Admiral Nurses:

- reduced call-outs of GPs
- Reduced inappropriate acute hospital admissions
- Reduced use of formal social care services
- Delayed transition from at-home to care homes, and care homes into nursing homes.

We also have compelling, independently validated evidence of the money that is saved by the employment of an Admiral Nurse, as follows:

- When employed in a community role: £480,000 over a year
- When employed in an NHS Acute Hospital: £215,000 over a year.

Before I close, I wanted to share with you the story of a lady, R*****, which she told me a few years ago.

7.R***'s story.**

Let me tell you the story of one person I know very well, R*****, and it is a harrowing but true story of a lady who wanted to describe some of the frustrations of trying to get consistent help and support whilst she was caring 24 hours a day, 7 days a week for someone with dementia.

Let me tell you R*****'s story as it was told to me:

“Sitting in the kitchen I saw John, my husband, put the cup on the tablecloth. I said, “John, please put the cup on the saucer”. I watched with increasing alarm as he lifted the cup, turned it slowly in his hand, put it on the table again, lifted the saucer and placed it on the cup - and then looked at me with heart-breaking bewilderment.

*I was frightened. I had had moments of fear before. I had seen looks of confusion on his face when he tried to write, how slowly he was now reading. I studied friends. Was this just an aging process? The word “**Dementia**” began to creep into my soul. It was a deeply hateful, frightening word.*

I want you to imagine my John, a smiling man, aged 65, six foot two, weighing 13 stone. Handsome, always immaculate, an international fashion designer who had travelled the world designing and selling luxury fashion.

Now I want you to imagine that same man gradually losing his speech, a man who screamed and snarled at me, a man who couldn't walk or talk, who frequently cried out as if in agony, and who finally died in hospital, weighing just over 7 stone”.

“One-day John woke at 3 in the morning, dragged me from my bed and tried to push me down the stairs. I ran out of the house in my nightdress, grabbing my phone and car keys and got in the car. He followed me, banging on the roof and windscreen, screaming and yelling.

No neighbour came to help, though we live in a quiet close. People are so scared of any form of mental illness, although they wouldn't be so scared if it was termed “brain damage,” which of course is what it actually is.

So I drove and drove. I could barely see I was weeping so much. When I calmed down and returned to our home, John was standing at the door and began to pelt me with whatever he could lay his hands on.

I rang Social Services - An answerphone!!

I rang 111 but couldn't cope with the never-ending questions.

Finally in desperation, I rang the police. When they arrived, very promptly, John was sitting on the doorstep smiling as though nothing had happened. He had no memory of it whatsoever.

It seemed the only choices given to me now to cope with his violent dementia were drugs – the infamous “chemical cosh”, or the police.

My own health deteriorated, I was bewildered and very, very frightened. This was a life I just wanted to end. One day my daughter said, “I’ve seen that you have hidden some of the knives.” She looked worried.

*She was right to be worried because I had planned how we could both die. No one seemed able to help, then out of the blue someone suggested that I ring the Admiral Nurse Helpline – **0800 888 6678** – a number forever etched in my memory.*

I did, and I swear that Admiral Nurse saved my life. We talked for more than an hour. She listened, she talked, she understood my grief and my pain, and put me in touch with the local Admiral Nurse who, from that very first day, immediately helped me support John through to his death”.

R*****’s story illustrates how Admiral Nurses are often the only thing that stands between carers and losing their sanity, and even their lives.

8.How together we are getting an Admiral Nurse service for Buckinghamshire and local area.

First let me thank you for all you have done to raise the profile of this need in Bucks.

In terms of what you can do, please share with us the contact details of potential commissioners/decision-makers/potential employers of Admiral nurses, and where you are able make introductions for us.

Continue to raise funds to continue the clinics and increase the pump-priming we are able to offer for a period of time to organisations that wish to employ (host) an Admiral nurse – it is part of our role to recruit only the very best nurses from the large numbers who apply for such a role. In 2013 we often had to advertise several times to find the quality of person we sought: today we are inundated with qualified mental health nurses wishing to become Admiral Nurses as the pinnacle of their professional lives.

Let me finish this brief presentation by once again thanking you for all that you do in the fields of caring for loved-ones, family members and friends. But we simply must get an Admiral Nurse service for Bucks.

The quality of a society is measured by the care and support we give to those most in need, and it difficult for me to think of doing other than working to help all those whose lives have become centred on caring for others.

Thank you.

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