



Becoming a Dementia Friendly Practice

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This paper should be read in conjunction with the Summary Document for Becoming a Dementia Friendly Practice April 2014 (toolkit with two attachments) and the Dementia Friendly Practice Quick Guide April 2014 Power Point

Becoming a Dementia Friendly Practice

April 2014

Introduction:

I am encouraged that in our area, Hampshire, there has been much focus and investment on developing Dementia Friendly communities which enable independent living for as long as possible. It became clear to me that GP surgeries are not currently very “dementia friendly”, but are set up instead to cater for people who are mentally able to navigate the system and yet patients with Dementia often look to us as key influencers in their health care needs. In 2013 our practice signed up to the Dementia Action Alliance and shared our vision to be more dementia friendly. Supported by a grant from the Academic Health Science Network I set out to interview my patients with Dementia and their carers to find out what we could do to make our practice more “dementia friendly”. The hope being that I could pull together an “action plan” which other practices could follow. A plan unique to a primary care setting.

Background:

Based on current projections, by 2021 there will be over 1 million people living with dementia in the UK (Alzheimer’s Society, 2012a). Currently this costs the NHS, local authorities and families £23 billion a year (Alzheimer’s Society 2007, updated to reflect 2012 figures). Only 44% of people with dementia in the UK have a diagnosis (Alzheimer’s Society) meaning that many people who are undiagnosed never receive appropriate treatments and care ([Dementia 2013 - the hidden voice of loneliness](#))

Nationally and internationally there has been a strong focus on improving the diagnosis, treatment and support for people with Dementia. The Prime Minister’s National Dementia challenge (March 2012) set out a plan to deliver major improvements in Dementia care and research by 2015. ([Prime minister's dementia challenge](#))

“Dementia sufferers’ needs for care start early in the disease course, and evolve constantly over time, requiring advanced planning, monitoring, and coordination. People with dementia merit special consideration in designing packages of care and support that meet their, and their caregivers needs. The challenge is to support ‘living well with dementia’ across the journey of care” ([World Alzheimer's Report 2013](#))

Becoming a Dementia Friendly Practice

April 2014

Dr Elizabeth Barrett from the Hardwick Clinical Commissioning group put together a helpful information toolbox for general practitioners and practice nurses. She describes “moving away from the concept of protecting the patient from the diagnosis (‘because nothing can be done’), and towards offering timely diagnosis to patients. We can raise awareness among the population as a whole and reduce the stigma of dementia and these social trends will tend to bring patients to us a bit earlier. When patients do present, we should be able to offer a pathway of diagnosis and care that is clear and can be done in a reasonable timescale.” ([Dementia the view from primary care](#))

In **The Dementia Action Alliance** – “Call to action” people with dementia and their family carers described seven outcomes they would like to see in their lives. ([National Dementia Declaration](#)). Some of these outcomes rely on primary care and require from us a change in the way we think and provide care to these patients and their carers.

1. I have personal choice and control or influence over decisions about me
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have the knowledge and know-how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future

NICE describes the standard of care we should aim to provide for people with dementia through the ten Quality standards listed below ([Dementia Quality Standards](#))

1. The health and social care professionals who care for you should have been **trained in the care of people with dementia.**
2. If your GP or another healthcare professional thinks that you might have dementia, you should be **referred to a memory assessment service** (this might be an appointment at a special clinic or with a mental health professional).
3. Your healthcare team should talk to you, and/or your carer(s), and offer you **written information about your condition, your treatment and the support that is available in your local area when you are diagnosed with dementia.**

Becoming a Dementia Friendly Practice

April 2014

4. You should be given a **care plan** that records the support that you will receive, gives the name of the person or people who will make sure the plan is followed and is written to address your particular needs.
5. You should have the opportunity, while you are able, to discuss and make decisions, together with your carer(s), about the use of:
 - a. advance statements (a set of written instructions saying what is to be done if you are no longer able to make decisions or communicate)
 - b. advance decisions to refuse treatment (a set of written instructions saying which treatments you do not want in the future)
 - c. Lasting Power of Attorney (allowing you to choose someone to make decisions for you if you are no longer able to make decisions for yourself)
 - d. Preferred Priorities of Care (a plan that allows you to make decisions about your care in the future, including where you would prefer to die).
6. **Your carer(s) should be offered an assessment of their needs.** If emotional, psychological and/or social needs are identified, they should be given support, such as psychological therapy and carer support groups.
7. If you develop symptoms that affect your mood and how you behave, which cause you significant distress, or your behaviour becomes challenging (for example, aggressive or agitated), you should be offered an **early and thorough assessment**. Treatments to help improve this behaviour or the distress it causes you should be recorded in your care plan.
8. If it is thought that you have dementia, or you have been given a diagnosis of dementia, and you are admitted to hospital or you attend an emergency department, you should have access to a healthcare professional specialising in dementia and older people's mental health, if needed.
9. If you are in the later stages of dementia, you should have your **palliative care needs (that is, care to help relieve the symptoms, such as pain or anxiety, of an illness that cannot be cured) assessed by your GP and this information should be shared with other members of your health and social care team.**
10. Your carer(s) should have access to services which provide the opportunity to take short breaks (or 'respite') that should be suited to their and your needs.

Becoming a Dementia Friendly Practice

April 2014

In April 2013 I was awarded a NICE Fellowship to explore the challenges and attitudes in primary care which may be blocking the implementation of the guidelines. I visited ten out of twenty practices in our CCG in 2013 to explore views and obstacles in the delivery of Dementia care in a primary care setting. Until the roll out of a National Direct Enhanced Service, which would encourage screening, there had been an apparent resistance to the notion of making an early diagnosis of dementia. This resistance to making a diagnosis remains, but is hopefully getting less.

Supported by a funding grant from the Dementia Challenge fund and the National Council of Palliative care our CCG offered 2 ½ hour workshops “From difficult conversations to better outcomes” for all GPs at every practice in our CCG. In these workshops we highlighted the need for a more proactive approach and the fact that early diagnosis is important if we are to support these patients in a way which meets their needs. Enabling our patients who have dementia to share their wishes at an early stage is crucial. We can then plan their longer term and end of life needs in an integrated manner, whilst involving and supporting their carer at the same time.

Our dementia friendly practice project:

[The National Dementia Prevalence Calculator](#) highlighted a significant dementia prevalence gap for our practice population. [The dementia partnerships resource pack](#) is a helpful toolkit for commissioners and emphasizes the importance of primary care. My practice has a larger than average elderly population, three nursing homes and one residential home in our practice area, but it seemed that we were missing many patients who had dementia. My first step was to review all our notes which made a reference to memory problem and ensure that those with a firm diagnosis of dementia were coded as such. [Paul Russell BMJ Dec 2013](#) has published a helpful paper with advice on coding and searches in a primary care setting. Our practice diagnosis rate has increased by 0.2% in the past 18 months, but it is thought to still be lower than it should be at approximately 53%. **Early identification and recognition of dementia** remains a crucial first step and this project has certainly raised awareness of dementia patients amongst all practice staff.

Having a clear understanding of the NICE guidance for Dementia care I wanted to facilitate a process where GP surgeries could move beyond a culture of tick boxing and be moved by patient stories in a way which would change behaviour in primary care and so-doing make the patient’s journey and that of their carer more positive.

Becoming a Dementia Friendly Practice

April 2014

The South West Dementia partnership put together a document in 2011 "[Dementia Partnerships Making Involvement Count](#)". This encouraged me to offer to meet with as many of our practice's dementia patients as possible. Over a one-month period I met with 15 different patients and their carers and asked them "what can we do to make things easier for you at our surgery?"

The strongest message was a need for the GP surgery to **involve the carer** in appointments and referrals. This has resulted in us amending our dementia template to encourage early consent to involve the carer in correspondence, which will enable better support for the patient and better attendance at surgery and hospital appointments.

My interviews with patients and their carers mirrored the work done by the Royal College of Nursing in 2011 ([SPACE acronym](#)). They published a commitment to the care of people with Dementia in General Hospital around the acronym **SPACE**. **S**taff who are skilled and have time to care, **P**artnership working with carers, **A**ssessment and early identification of dementia, **C**are plans which are person-centred and individualized, **E**nvironments that are dementia friendly. The one additional factor, which we felt was important, was to **identify a Dementia champion** within the practice, so we added an "i" making it **iSPACE**.

Engagement with the **whole practice team** resulted in some excellent ideas around the processes which needed to change to make our service delivery more suitable for people who had problems with their memory. **Staff training** which was led by a facilitator who used an activity which gave us some insight in to the frustrations of having dementia, the feeling of being unable to remember something or complete a task was a powerful enabler and encouraged the process changes in our organisation. These changes included prompts to remind patients with dementia of their appointments, the need for longer appointments and the importance of continuity of care with one clinician. Patient stories and personal experience are remarkably powerful as drivers for change – examples of useful materials include [Dr Jennifer Bute's personal experience and short training videos](#) as well as the material produced by the Alzheimer's society on [how to help people with dementia](#).

Supported by an administrative assistant we are now more proactive. Their dementia review appointment invitation is sent to them and their carer, with a helpful contacts card and a "[This is me](#)"

Becoming a Dementia Friendly Practice

April 2014

document. We encourage patients to bring this with them to their annual review appointment. Once we have scanned it on to their notes they keep the original document and this can then be the foundation for future care planning and be sent with them to hospital if they are admitted.

The **carer information is coded** and we are now much proactive about involving them (with the patient's consent) in follow up appointments and hospital referrals. They are also better supported and have in the past year been able to attend carer clinics which have been run by the Princess Royal Trust for carers (funded by a dementia challenge funding grant).

The need for **anticipatory care planning** has been highlighted through workshops and meetings. Greater awareness of the natural progression of dementia and the challenges of symptom assessment has meant that we are more likely to use some of the tools available such as [FAST staging](#) tool for dementia when the MMSE can no longer be used. We are now more likely to make an objective assessment of pain in advanced dementia using a tool such as [PAINAD tool](#).

The recent introduction of the **National Admission Avoidance Direct Enhanced Service** and the updated **National Dementia Direct Enhanced Service** with an additional focus on care planning will, we hope, have a positive impact on care for patients with dementia in primary care.

We've ensured that our signage in the waiting room is dementia friendly. The Kings Fund document ["is your ward dementia friendly?"](#) gives some helpful ideas. Clear signs for the toilets can be ordered from [Alzproducts](#) or [dementia signs](#) and these are inexpensive (approximately £14 each)

As we raise awareness of dementia and as the prevalence increases along with other long term conditions in an ageing population we strive to support our patients on their care journey. The benefits of being a dementia friendly practice are thus far unmeasured. We hope to show

- Improved **patient and carer experience** with reduced stigma to the diagnosis of dementia
- Improved **teamwork**
- Improved **clinical consultations** – better prescribing and improved referrals
- Improved **care planning** for the future
- Improved **quality of life** for our patients

Becoming a Dementia Friendly Practice

April 2014

Having taken some time to listen and implement organisational changes needed we are now in a better position to offer the compassionate, personal care that our patients with dementia and their carers deserve and desire. We will be looking to them to hold us to account.

We have put together an action plan for becoming a dementia friendly practice. This consists of a summary document with two attachments and a power point slide show. We hope that the steps we've taken will have a measurable impact on those who need it most – our patients and their carers.

Information Sources:

- **Dementia 2013: The hidden voice of loneliness is Alzheimer's Society's annual report examining the quality of life for people with dementia**
- **Dementia: 10 key steps to improving timely diagnosis third edition Jan 2014 Kate Schneider**
- **Dementia - the view from primary care. A toolbox for use by GPs and practice nurses. Dr Elizabeth Barrett. Hardwick Clinical Commissioning Group. July 2013**
- **Enhanced Service Specification: Facilitating timely diagnosis and support for people with dementia NHS England gateway reference: 01409**
- **Improving the identification of people with dementia in primary care: evaluation of the impact of primary care dementia coding guidance on identified prevalence ; Paul Russell BMJ 23 Dec 2013**
- **Involving People Living with Dementia – making involvement count. Torbay Leadership Group 2011**
- **The Kings Fund “is your ward dementia friendly?” EHE environment assessment tool 2013**
- **NICE Dementia Quality Standards (QS1) issued June 2010**
- **Prime Minister’s challenge on dementia: Delivering major improvements in dementia care and research by 2015 (Department of Health)**
- **RCN: Commitment to the care of people with dementia in general hospitals; 2011**
- **The National Dementia Declaration**
- **World Alzheimer’s Report 2013**