Dementia Friends and *focal point*

Fry’s, Keynsham

Thursday 16\(^{th}\) January 2014

Anne Cole – CPPE Regional Manager SW
Thank-you

• Avon LPC
• Dementia Friends and Alzheimer’s Society
• CPPE

Congratulations to Avon LPC on their success in winning from Pinnacle Health Partnership an award to pilot a dementia identification service
Objectives

By the end of this session you will:

• have a better understanding of dementia
• know a little bit more about what it is like to live with dementia
• be aware of some small things that could make a difference to people living in our community
• be aware of five key facts about dementia
• be inspired turn your understanding into action
• be a Dementia Friend!
Hopes and concerns?
Why am I here?

• Dementia Friends piece on BBC breakfast
12\textsuperscript{th} February 2013
National dementia strategy
‘Living well with dementia’
February 2009

Aim: to ensure that significant improvements are made to dementia services across three key areas:

• improved awareness
• earlier diagnosis and intervention
• higher quality of care.
The Prime Minister’s challenge on dementia March 2012

Three key commitments:

• Drive improvements in health and care

• Create dementia friendly communities that understand how to help

• Better research.
National context

• there are an estimated **800,000** people with dementia in the United Kingdom
• Around **17,000** of these people are aged under 65 years
• **a quarter** of hospital beds are occupied by people aged over 65 years with dementia at any one time
• by 2021 there will be over **1 million people** living with dementia in the UK
• dementia currently costs the NHS, local authorities and families **£23 billion a year** (£27 billion by 2018).
International context

G8 dementia summit, London 11th Dec 2013.

Commitments:

• Cure, or a disease-modifying therapy for dementia by 2025
• Increase research into dementia
• Share information and data
• New global envoy for dementia innovation
NHS England dementia map
http://dementiachallenge.dh.gov.uk/map
Dementia diagnosis rates

The Prime Minister’s Challenge on Dementia set out the ambition to improve diagnosis rates:

By 2015, two-thirds of people should have a diagnosis, with appropriate post diagnosis support.

<table>
<thead>
<tr>
<th>Diagnosis figures</th>
<th>2013 (2012):</th>
<th>estimated no.</th>
</tr>
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<tbody>
<tr>
<td>Bristol CCG</td>
<td>49.7% (48.9%)</td>
<td>4425</td>
</tr>
<tr>
<td>South Gloucestershire</td>
<td>47.1% (36.5%)</td>
<td>3255</td>
</tr>
<tr>
<td>North Somerset CCG</td>
<td>43.5% (39.7%)</td>
<td>3565</td>
</tr>
<tr>
<td>BaNES CCG</td>
<td>41.8% (39.7%)</td>
<td>2575</td>
</tr>
</tbody>
</table>

Total estimated number of people with dementia in LPC area = 13820
Dementia Friends’ information session
What is the Dementia Friends about?

Dementia Friends is a national initiative that aims to improve people's understanding of dementia and its effects:

• run by the Alzheimer’s Society
• funded by the government.
Dementia Friends
- the need

• 44% of people with dementia feel they lose their friends after being diagnosed
• 48% of people with dementia feel like a burden to their family
• 61% of people with dementia feel lonely always or some of the time
• 67% of people with dementia do not always feel part of the community
• 75% of people in the UK don't think society is geared up to deal with people with dementia
• 77% of people with dementia feel anxious or depressed.
Dementia Friends aims:

• recruit one million Dementia Friends by March 2015
• challenge stigma and improve understanding of dementia and its effects
• turn understanding into practical action to help people to live well with dementia in their communities
• supporting the ambition to make communities dementia friendly.
What is a Dementia Friend?

• a Dementia Friend is someone with an understanding of dementia and the small things that they can do that could make a difference to people living with dementia

• people with dementia sometimes need a helping hand to go about their daily lives and feel included in their local community
  eg. • helping someone to find the right bus
  • spreading the word about dementia.
Five key things everyone should know about dementia
Myth: ‘dementia is a natural part of growing old’
Key fact 1 - dementia is not a natural part of growing old

As you grow older do you find?
• You forget people’s names more easily?
• Words won’t come as easily?
• Getting to the top of the stairs and thinking “what did I come up here for?”
• Your brain generally does not seem quite as ‘whizzy’ as it used to be?
• If so, DON’T WORRY – THIS IS NORMAL!
However if it starts to affect your daily life, for example:

• forgetting whole events or conversations not just names and details
• finding that memories do not come back even with prompting
• getting lost in familiar, rather than new, places
• finding it difficult to keep up with events and becoming disorientated
• frequently repeating conversations
• showing signs of progression in terms of frequency and severity of problems.

Consult your doctor
Myth: ‘dementia is when a person just loses their memory’
Making a cup of tea

- Your turn to do something!
Key fact 2 - dementia is not just about losing your memory

Dementia is a term used to describe a group of symptoms.
Some symptoms of dementia

• Core features – difficulty with:
  – memory – new learning
  – thinking – drawing everything together
  – communication – language and understanding
  – functioning – difficulties with everyday tasks - planning, concentrating, organising and decision-making

• Specific difficulties with:
  – spatial awareness
  – perception – people in the room who are not there
  – mood or behaviour

• Symptoms are variable but overall dementia is progressive.
The bookshelf model of memory

Memories

• Memories like books on a bookshelf
• Stored over time
• Most recent on top
• Hippocampus – factual data (plywood bookcase)
• Amygdala – emotions and feelings (oak bookcase)

Person with dementia

• Bookshelf wobbles
• Top shelf books affected first
• Progressively lower books fall
Key fact 3 - dementia is caused by diseases of the brain

- dementia is the result of brain cells being damaged in an ongoing way
- this happens as a result of a number of different diseases, sometimes referred to as ‘types’ of dementia.
Types of dementia

- Alzheimer's disease 62%
- Vascular dementia 17%
- Mixed dementia 10%
- Lewy body dementia 4%
- Fronto-temporal dementia 2%
- Parkinson's disease dementia 2%
- Other dementias 3%
Conditions that may get confused with dementia

- delirium
  - anaemia.
  - low blood sugar
  - diarrhoea / constipation
  - medicines or combinations of medicines
  - infection
  - post surgery

- depression
- pain
- poor sight or hearing
- tumours
- vitamin B deficiency
- underactive thyroid gland
- sudden life changes.
Myth: ‘dementia means you will become incapable of living life with any meaning’
Key fact 4 - it is possible to live well with dementia
Stigma and denial

• affected families sometimes do not welcome offers of help – stigma and denial are big problems
• most of us experience emotion in the face of dementia
  - fear
  - grief
  - misplaced guilt.
Key fact 5 - there is more to a person than their dementia

- each person with dementia will respond to the difficulties they experience in an individual way

“I will remember that each person with dementia is an individual with their own story and treat them accordingly”.

- for some people having a range of difficulties in memory and thinking can result in a person feeling:
  
  ....Frustrated
  ....Angry
  ....Upset
  ....Distressed
  ....Alone
  ....Frightened.
Communicating with a person with dementia

• ask first and smile
• listen carefully - give the person time to respond.
• maintain eye contact
• speak calmly and clearly
• use short sentences giving a small amount of information.
• use open body language
• offer support
• consider feelings
• show respect
Supporting the person with dementia

Try to......
• involve the person, wherever possible in making decisions about everyday matters
• make time to listen to the person
• show kindness and be reassuring
• respect the person at all times.

Try not to.......... 
• be or appear cross with the person
• argue with the person
• ignore the person.
Recap - five key things everyone should know about dementia

- dementia is not a natural part of growing old
- dementia is not just about losing your memory
- dementia is caused by diseases of the brain
- it is possible to live well with dementia
- there is more to a person than their dementia.
Local initiatives

- BaNES Dementia Strategy
- Bristol & South Gloucestershire Dementia Strategy
- North Somerset Dementia Strategy
- Joint health and wellbeing strategies
- Dementia partnerships
- Our health South West
- Patient support groups
Signposting

- Alzheimer’s Society  [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
  - factsheets and leaflets
  - training and resources
  - discussion forums
  - memory cafés and singing for the brain
  - befriending services
- Dementia Friends  [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)
- Dementia UK  [www.dementiauk.org](http://www.dementiauk.org)
- Dementia Action Alliance  [www.dementiaaction.org.uk](http://www.dementiaaction.org.uk)
- Dementia Partnerships  [http://dementiapartnerships.com](http://dementiapartnerships.com)
- Age UK  [www.ageuk.org.uk](http://www.ageuk.org.uk)
- Dr Jennifer Bute  [www.gloriousopportunity.org](http://www.gloriousopportunity.org)

- Avon LPC:  [http://psnc.org.uk/avon-lpc](http://psnc.org.uk/avon-lpc)

NICE Dementia pathway, guidelines, technology appraisals, quality standards  [http://www.nice.org.uk](http://www.nice.org.uk)

NHS dementia map  [http://dementiachallenge.dh.gov.uk/map](http://dementiachallenge.dh.gov.uk/map)
Opportunities for pharmacy

- Community pharmacists and their teams are well placed, at the heart of local communities
- Over 1.8 million people visit a community pharmacy in the UK each day
- Public health
- Raise awareness and signpost people and carers
- Early diagnosis and support
- Medicines optimisation – not just antipsychotics!
What next?

- Some ideas for action

• understand more about it

• change your own attitude – learn to stand against the difficult emotions

• challenge the attitudes of others (with sensitivity)

• offer help to someone you know who is affected
  - be willing to try
  - be willing to feel uncomfortable
  - be willing to get it wrong

• volunteer in your local community

• become a Dementia Friends champion
You are now a Dementia Friend - Congratulations!

- You can now proudly wear your Dementia Friends badge and tell people what it means.
- Dementia Friends information card to remind you about the 5 key facts about dementia.
- Visit www.dementiafriends.org.uk to sign up as a Dementia Friend and register your action.
- Consider becoming a Dementia Friends Champion and spreading the word yourself.

Alzheimer’s Society
Leading the fight against dementia
And now it’s time for……

• CPPE dementia *focal point* case study on page 6 of book 2

• Arthur

**NICE - stages of dementia**

• Mild dementia MMSE: 21-26

• Moderate dementia MMSE: 10-20

• Severe dementia MMSE: Less than 10
The patient and his family have been told that Arthur will be prescribed an acetylcholinesterase inhibitor used for the treatment of dementia. Excluding pharmacological treatments, what other advice can you give to help them manage the disease at this stage? (We can think of at least 5).

Text between question 2 and 3:
Delete the first sentence “Over the next year, Arthur’s wife often visits your pharmacy and informs you that Arthur’s condition is deteriorating.”

NICE - stages of dementia
• Mild dementia MMSE: 21-26
• Moderate dementia MMSE: 10-20
• Severe dementia MMSE: Less than 10
Complete:

• Reading, practice points and clinical vignettes
• Putting your learning into practice p13-14 book 2
• Directing change p38-39 book 1
• CPPE dementia *focal point* e-assessment [www.cppe.ac.uk/assessment](http://www.cppe.ac.uk/assessment)
• CPD entry [www.uptodate.org.uk](http://www.uptodate.org.uk)
• Dementia Friends Champions training [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)
• Tell your friends and colleagues!
Next CPPE workshops

• Antibacterials *focal point* 7:30 – 9:00pm: Swindon, Thu 13th Feb *(Only 1 place left)!* (Bath & Bristol events full)

• Inhaler technique training 7:30 – 9:30pm: Cheltenham Tue 4th Feb *(Only 2 places left)!* (Bristol and Weston events full)

• Clinical study day for pharmacists (renal, antimicrobials, anticoagulation) Bristol, Sat 15th Mar 10:00-4:30pm *(Only 6 places left)!*

• Working together for patient safety: a full day GP and pharmacist learning event (dementia focus) Swindon Wed 26th Mar 10:00-4:30pm *(Only 6 places left)!*

• Primary care conference: sharing evidence based practice Bristol, Mon 19th May 9:45 – 4:15pm
In the meantime there’s plenty more learning from CPPE!

• e-challenge – fortnightly fun quiz for all
• Brand new! Medicines quiz app (available at the App store and Google play very soon)
• Medicines safety app soon
• e-learning and e-courses
• podcasts – e.g. Healthy living pharmacies or preventing medication errors
• e-lectures
• guides – e.g. self care, time management or peer feedback
• theLearningpharmacy.com at [www.thelearningpharmacy.com](http://www.thelearningpharmacy.com) - depression, smoking, COPD, NSAIDs, cancer, palliative care, child health and sexual health and dementia to follow soon!
• annual learning check
• learning communities
Apps

• CPPE app and ‘e-challenge’ pharmacy/medicines news quiz:
• ‘Medicines quiz’ app
• ‘Medicines Safety’ app (soon)
Pharmacy (medicines) news
e-challenge
Thank-you

- For all your hard work and participation
- Please complete evaluation forms
- Sign attendance sheets
- See you again at another event soon!
- Goodbye and have a safe journey home