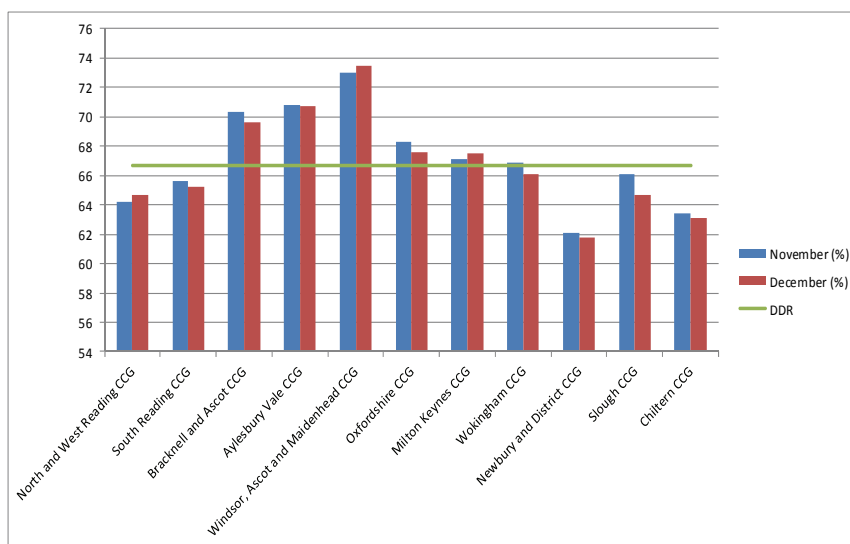


Inside this issue: End of Life care for people with dementia, plus helpful resources

Dementia Diagnosis Rates

Thames Valley CCGs have collectively achieved a dementia diagnosis rate of 66.8% (December 2017)



Healthwatch Wokingham Borough trials a new dementia friendly environment assessment tool



Healthwatch Wokingham Borough have developed a new tool to assess how dementia friendly environments are. The tool assesses:

- * Physical environment (communal/personal spaces, familiar objects, signage, furniture, visual access, colour, lighting and outdoor spaces)
- * Social environment
- * How person-centred the care is
- * Staff communication and engagement with people with dementia, their relatives and visitors.

To test the tool, Healthwatch Wokingham Borough visited Suffolk Lodge, a home providing accommodation and care for people who have care needs related to old age or dementia. Healthwatch Authorised Representatives assessed the home against the dementia friendly tool, made observations and subsequently recommendations to further assist people with dementia to live well. Read the report here: <http://bit.ly/2Dp5PiX>

If you would like Wokingham Borough to visit your location, get in touch with them here: <http://bit.ly/2DuuT8e>

Feature: End of Life and Dementia

End of life care should support people with dementia to live as well as possible until they die. Dementia is not a terminal illness but it does shorten lives. A person diagnosed with dementia will live, on average, for another 10-12 years. Patients often die as a result of their frailty rather than the dementia itself, e.g. pneumonia or falls. Dementia involves a progressive decline in cognition, function, behaviour and care needs and it is wise to make plans well in advance of a person's condition deteriorating.

A peaceful, 'good death' can be provided through good planning and support for patients with dementia.

Each person diagnosed with dementia should have a care plan and this should be reviewed at least annually with their GP (supported by QOF). End of life care should be a key element of the plan. These plans are supportive for the patient, but also for their carers and their health professionals. Preferences for end of life care should ideally be discussed and set out soon after a diagnosis of dementia, whilst the patient is still able to make decisions for themselves.

1. How would you like to be cared for, where and by whom?
2. Resuscitation decisions
3. Advance Decisions (Living Wills) regarding treatment (antibiotics, admissions etc.)
4. Wills
5. Lasting Power of Attorney
6. Spiritual considerations



Planning for Emergency Care and Treatment

[The ReSPECT process](#) (Recommended Summary Plan for Emergency Care and Treatment) supports the wider advance/anticipatory care planning process. It creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. Such emergencies may include death or cardiac arrest, but are not limited to those events. The process is intended to respect both patient preferences and clinical judgement.

The recorded succinct plan is intended to provide rapidly accessible information for professionals faced with an emergency, to help them to make immediate decisions that respect the person's wishes and their clinical needs.

How do we know when a person with dementia is approaching end of life?

It can be difficult to know when a person with dementia is approaching end of life. The FAST (Functional Assessment Staging Tool) is a functional scale designed to evaluate patients at the more moderate-severe stages of dementia. By identifying the stage of dementia, appropriate care can be given to the patient and their carer (see p.3).

How do I provide good end of life care for people with dementia?

Good end of life care for a person with dementia involves a number of different professionals working together: GP, community nurses, specialist dementia nurses, social workers or care home staff. Palliative care professionals at a local hospice or hospital may give specialist input if this is needed.

End of life care should support the person to live as well as possible until they die, and according to their wishes outlined in their care plan:

- * addressing their physical needs (including pain relief and management of other symptoms)
- * being treated with compassion and respect
- * being kept clean, comfortable and free from distressing symptoms
- * being in a familiar place surrounded by those close to them.

Palliative care focuses on maintaining a person's quality of life by relieving discomfort or distress

- * medication to relieve pain and agitation
- * carer support and respite
- * appropriate equipment (continence pads, hospital beds etc)
- * general nursing and support.

End of Life and Dementia: Resources

FAST scale

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0

Weblinks

- * [ReSPECT tool](#)
- * [Alzheimer's Society: advance decisions and advance statements](#)
- * [Compassion in Dying: making decisions and planning your care](#)
- * [Age UK: advance decisions and advance statements](#)
- * [Macmillan Cancer Support: advance care planning](#)

NHS-approved apps



The NHS has released a list of NHS-approved apps that can be shared with patients:

<http://bit.ly/2F7jLPf>

Included in the list is Talking Point, an online community run by the Alzheimer's Society, for any affected by dementia including friends, family and carers. It is free to download; users will need an account on the Alzheimer's Society to start chatting.

Multi-language dementia videos



Bristol's Dementia Wellbeing Service has produced the video 'Your Questions Answered - a film about dementia', and translated it into the six most spoken

languages in the town: Cantonese, English, Polish, Punjabi, Somali and Urdu. View the videos here: <http://bit.ly/2DA0kSZ>

The video features clinicians, patients, and community representatives, and signposts the help and support available for people diagnosed with dementia.

Oxford AHSN webinars

Oxford AHSN host a number of dementia-related webinars, covering topics such as people with dementia getting lost, management of dementia with Lewy bodies, and CBT for people with dementia.

They are also hosting the following upcoming webinars:

Wednesday 7th February, 12:30-13:30 **Dementia and Diabetes**

Wednesday 7th March, 12:30-13:30 **The Challenge of Multimorbidity in Dementia**

To get a link to the webinar recordings, or to sign up to updates from the AHSN dementia network, email Fran Butler: fran.butler@oxfordhealth.nhs.uk

Life story work in dementia care



The University of York has undertaken a research study into good practice in life story work. Life story work involves recording aspect of a person's past and present lives, which can be of benefit for people with dementia to reinforce their sense of identity and aid communication.

As a result of its research, the group has produced a set of good practice guidelines which include:

- * a reminder that not everyone wants to make a life story
- * the person with dementia should be involved in making decisions
- * helpers should be appropriately trained and supported
- * the life story should be updateable.

The findings are based on a systematic review of the literature and 10 focus groups with people with dementia, family carers and professionals (with a total of 73 participants).

The University has created a five minute video on the findings of the project, and can be used by anyone for non-commercial purposes for staff training or awareness. View the video here: <http://bit.ly/2n3bvsU>

They have also produced a summary of the research findings which can be viewed here: <http://bit.ly/2F40IVP>, and the full report is downloadable here: <http://bit.ly/2DueSiy>

Got something to share?

If you have an event, a website, a new application or anything you'd like to share with dementia professionals across Thames Valley, let us know! Contact Sian Roberts (sian.roberts2@nhs.net) or Sylvie Thorn (sylviethorn@nhs.net).