

Advance care planning in diagnostic memory services

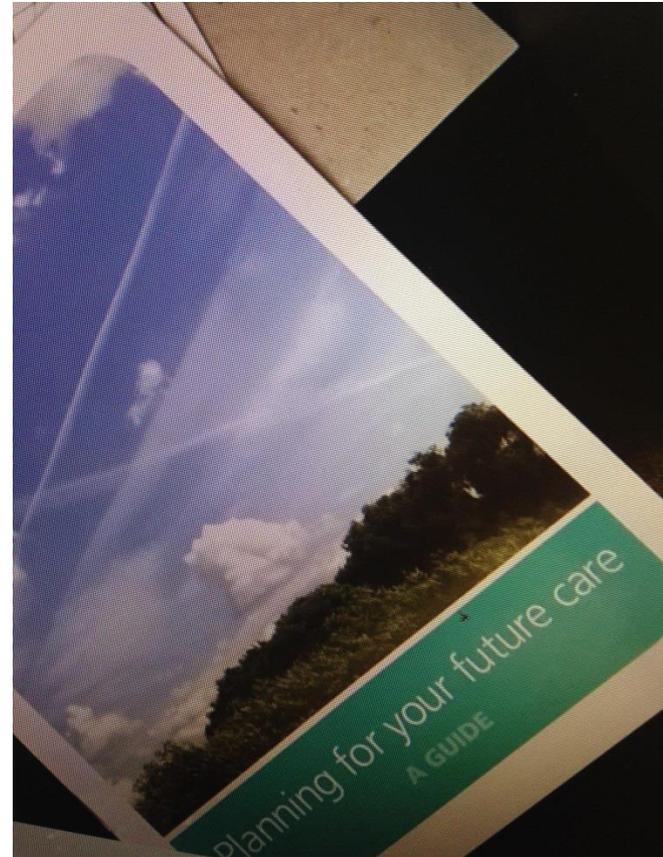
Dr Juliette Brown, Higher Trainee in Psychiatry, City and Hackney
Dr Tom Smith, Consultant Psychiatrist, Newham

London Memory Assessment Network Meeting
7 September 2016

Today:

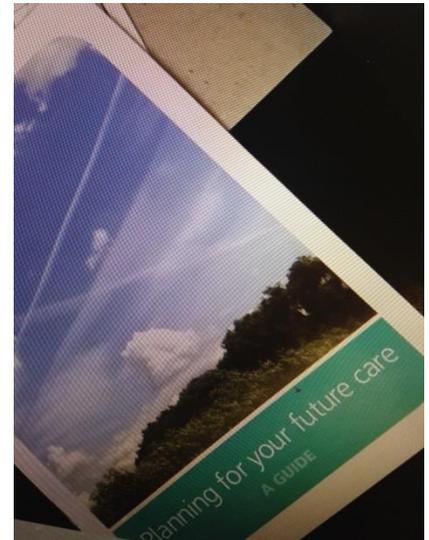
- *Your understanding of ACP*
- *Barriers*
- *Why might people with dementia want to plan ahead?*
- *How do we make this happen in memory services?*
- *What's it like in practice?*
- *Your thoughts?*

Your understanding of ACP?



Your understanding of ACP?

- Process of discussion
- In a life limiting illness
- Wishes and views on future care
- Formalised in AS, ADRT and LPA



Barriers

- Theoretical good with limited evidence base
(*Dening et al, 2011; Robinson et al, 2012, Brinkman–Stoppelenburg et al 2014*).
- Professional barriers – concern over responsibilities, legal aspects, timing..
(*Robinson et al, 2012*)
- Barriers in 4 domains: disease, patient, professional, services- lack of confidence, skills, knowledge, anxiety about discussing EoL, lack of tools and resources, service configuration (*Brown, 2015*).

Evidence of benefit outside of dementia?

- Prospective cohort RCT of discussion on advance directives involving 686 patients - sustained and significant improvement in patient reported experience measures - *Tierney et al, 2001*
- RCT of ACP in patients at EoL— much more likely for wishes to be recorded and followed, less stress, anxiety, and depression in carers - *Detering et al 2010*
- Longitudinal cohort of pts at EoL – ACP did not increase psychological distress, far less aggressive treatment in the ACP group, better QoL at EoL and better caregiver adjustment to bereavement - *Wright et al, 2008*

Evidence of benefit in dementia?

- Qualitative study 12 patients and 8 carers after ACP discussion – positive intervention, less worried about the future - *Poppe et al, 2013*
- Qualitative study with 5 patients – increased control and autonomy - *O'Kelly et al, 2015*
- *2016 data from East London* – aware of the gap that people face after diagnosis, allows clinicians to be person-centred, to help people retain control, and sense of self, clarify family assumptions, to open a discussion about prognosis. Takes advanced communication skills and expertise, but not as difficult as anticipated.

Why plan for the future?

‘I have personal choice and control or influence over decisions about me.’

‘Effective post-diagnosis support allows people with dementia to access appropriate information, make adaptations to the condition and plan for the future.’

Alzheimer’s Society Annual Survey, Dementia 2015



Why plan for the future?

‘There’s a lot of talk about being patient focused, but you have to know what they want..’

‘If there never been an honest discussion, it can be horrific..’

‘With the diagnosis, the emphasis is on the disease. With ACP, the person is delivered to the fore, you become the centre’



‘It gives permission to talk..

Clawing control back...

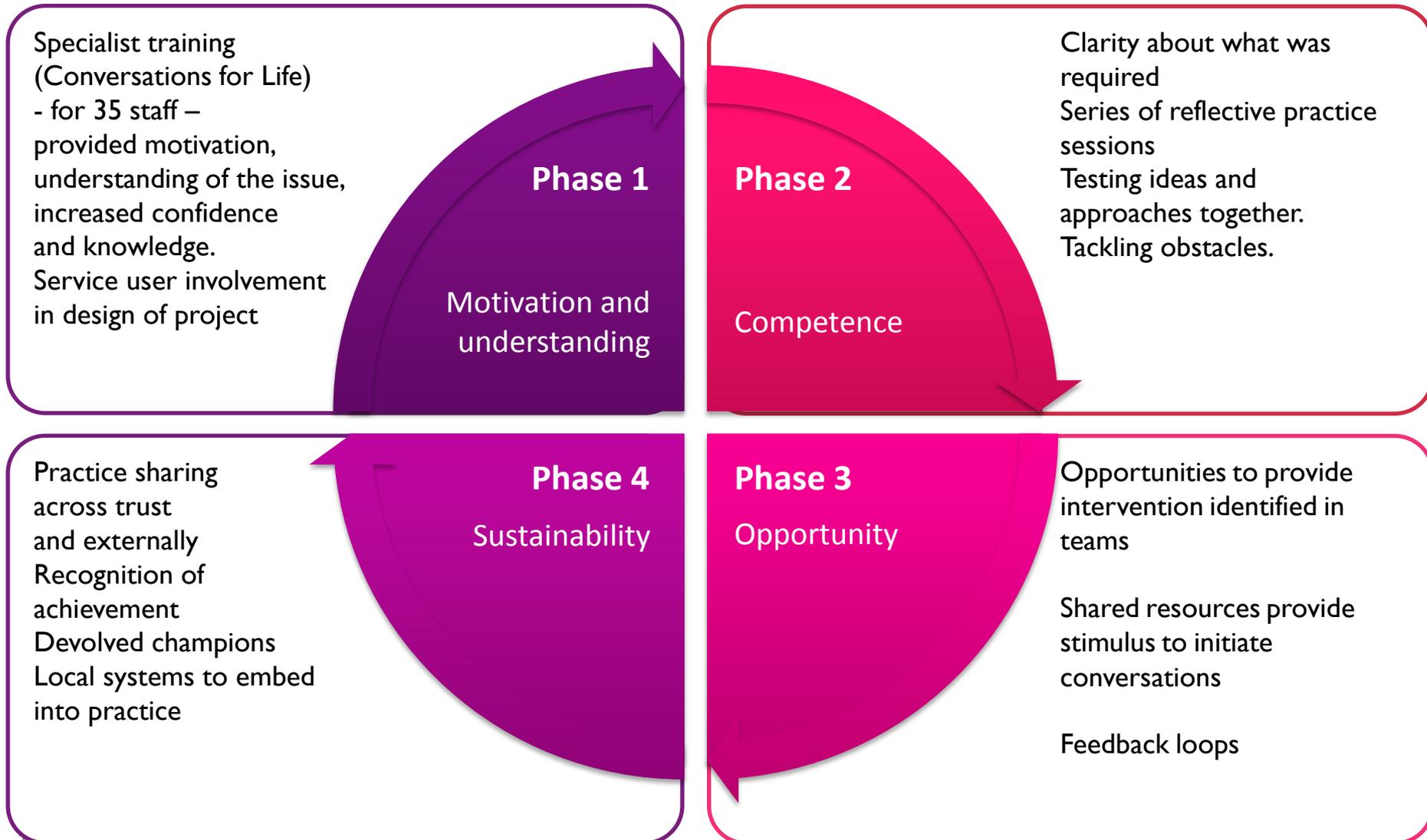
Take control of the illness rather than it controlling you..’

‘This has helped bring us back to the patient’

‘We have fallen in love with ACP
and we want it to continue’

What did we do?

Using a behavioral change model to deliver ACP in MS



Originator:SMITH, Tom (NH) Detail

13 Jul 2016, 16:24 [MH Medical - Consultant]

Letter to GP Date of clinic: 5/7/2016

Newham Memory Service Assessment – Final Report

NAME DOB Diagnosis

1. Dementia in Alzheimer's disease, very mild, ICD code F0 0.1

Plan

- 1. We have started him on donepezil 5 mg once a day PO, and will follow this up in our medication clinic.**
- 2. We have discharged him from further diagnostic assessment in the Newham memory service.**
- 3. We will contact him to offer a brief post-diagnostic advice and support session.**

Recommendations for GP - none

Thank you for referring X to the Newham Memory Service. He attended the feedback session on 5 July 2016, together with his wife.

Assessment Summary

In writing this report, I have drawn on the detailed initial assessment report by Dr Adam Fyffe, following interview on 26 February 2016, and 4 March 2016.

In brief summary, **X** is ... aware of having memory problems, and finds it very frustrating. His family feel it has been going on for 4 years, but most noticeable in the last two years. He becomes very disorientated in time, is very repetitive in conversation, occasionally forgets things completely, and is more anxious and irritable (which is unlike him). He remains fairly independent in his activities of daily living, but is starting to need more assistance. The past medical history includes elevated cholesterol, and more recently, falls. Although he had an episode of depression in 1999, and has a strong family history of mental illness, he is not currently presenting with marked anxiety or depressive symptoms.

Investigation Results

The dementia screening bloods from 27 January 2016 were unremarkable. The MRI brain from 3 May 2016 showed mild generalised atrophy, mild ischaemic brain disease, and normal hippocampi.

Cognitive Findings and Conclusion

On neuropsychological testing, he had variable but reduced delayed verbal recall, poor semantic fluency, very poor dual processing, and had difficulties drawing a clock.

The test results, together with the cognitive and functional decline, suggest that X is currently suffering from the early stages of a dementia.

The overall picture is consistent with a diagnosis of Alzheimer's disease.

Information sharing

He was offered the following correspondence: A copy of this letter –accepted. A copy of this letter for a carer or friend -declined

Advance care planning: He expressed an interest in having a more detailed conversation about advance care planning, and appeared to have capacity to agree to this. We will offer this consultation as part of our post-diagnostic advice and support session.

Summary of feedback meeting: The diagnosis of very mild dementia in Alzheimer's disease was discussed with X and his family. We have provided a copy of “The Dementia Guide”, published by the Alzheimer’s Society.

We will contact him to see if he is interested in the therapeutic groups that we run for people with this condition. We explained the various pros and cons of donepezil ... We gave X advice about driving ... We are now discharging him from further diagnostic assessment. Thank you for referring X to our service for an assessment of his memory.

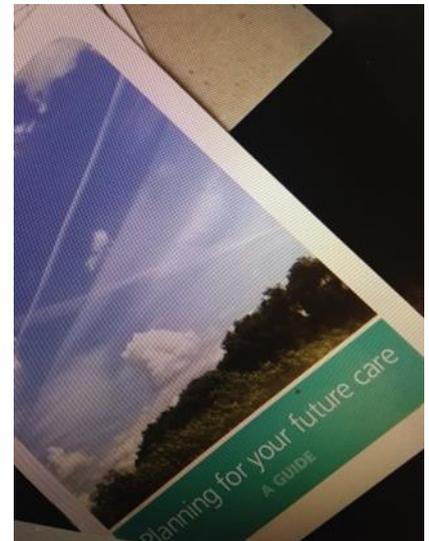
Yours sincerely Dr Tom Smith, Consultant Psychiatrist, Newham Memory Service cc: patient

3 Aug 2016, 13:50 [MHTherapy - Psychologist]

Attended and seen with his wife for post-diagnostic support & advice session. Both engaged well. Offered to see separately but this not taken up. Various topics were usefully covered. LPA and ACP both discussed, and information provided.

PLAN

Remain under service as scheduled for medication review next week.



October 2014 – June 2016

People with new dementia diagnosis offered
ACP initial discussion and follow up



Now?

- Step change in HCP attitudes
- Increased confidence in discussing ACP
- Increases willingness of patients to discuss ACP
- Memory service staff are ideally placed to start this work.

- Ongoing issues: Denial, difficulty accepting the diagnosis, knowledge about the course of the illness, service capacity and service configuration.

The future?

- A willingness to better support patients after diagnosis
- Not waiting for evidence on long term outcomes
- Encourages person centred practice that is psychologically minded as well as practically helpful
- Services for post-diagnostic support
- Look to wider system – part of MS accreditation?
- Look to wider system – link in to primary care, acute services, palliative services?? And accept that there is value to person-held knowledge and private discussions ...

With thanks..

Dr Anna Moore, Director, Integrated Mental Health Programme UCL Partners; Dr Caroline Stirling, Clinical Lead and Consultant in Palliative Medicine, End of Life Care Lead UCLPartners ;Laura Stuart, UCLPartners; Dr Amar Shah, Associate Medical Director, East London NHS Foundation Trust; Dr Kevin Cleary, Medical Director, East London NHS Foundation Trust; Neil Ralph, Anthony Senner and James Cain at HENCEL. At City and Hackney: Dr Sandra Evans, Richard Reynolds, Dr Emma Teper, Nick Mooney, Marianne Roots, Ahmet Karabiyikli, Sameer Joomun, Steve Reading, Martyn Cooper, Fatima Kamara. At Newham: Dr Tom Smith, Ruth Lisk, Sipho Malinga, Alex Lewis, Adam Fyffe, Pauline Davis, Lesley Smith, Dr Mina Bobdey, Claire Smith. At Tower Hamlets: Corinne Drummond, Leores Britanico, Jonny Stockdale, Mary-Ann Tait, Sam Ahulu, Veronica Samuel , Fatima Begum, Christine Hopkirk, Dr Nick Bass. Dr Cate Bailey, Sarah Mills and Jean Campbell. Ken Courtney at Barnet, Enfield and Haringey Mental Health Trust. Suzanne Joels and Emily Van der Pol at Camden and Islington NHS Foundation Trust. Stephen O'Connor, Joanne Rodda, Janet Carter and Stephen Clements at North East London NHS Foundation Trust. Charles Olujugba at South Essex Partnership Trust. Dr Hugo De Waal, Ruth Evans, Strategic Clinical Network for Dementia.

Your thoughts?

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