



# Joined up care; lessons from dementia

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*Improving lives*



## Living and dying well with frailty

- Not the same as “End of Life”.
- Living well
- Appropriate supportive and palliative care
- Sensible care which is not burdensome.
- In advanced dementia discussions about palliating distress are very helpful
- Discussions about limiting care as life is short are do not go well and are much less helpful
- And we know that prognosis is not helpful with dementia and frailty
- Therefore palliative and supportive care is based upon need

## Indicators for a more palliative approach in dementia

1. Does the patient have moderately severe or severe dementia?
2. Does the patient **also** have
  - Severe distress (mental or physical) which is not easily amenable to treatment?
  - Severe physical frailty which is not easily amenable to treatment?
  - Another condition (eg. co-morbid cancer) which merits palliative care services in its own right?
- 
- If criteria 1 and 2 co-exist, then the patient ought to have a full assessment of need and a focused analysis of why they are in distress and how best their symptoms can be improved and distress reduced.
- Source The Power of Partnership: Palliative Care in Dementia. Pub National Council for Palliative Care, 2009

## How does that work?

- Works well,
- Identifies people at need of advanced and palliative care of dementia
- Supports good care
- Alongside discussion distress supports helpful family engagement and agreement.

What would you want if you were suddenly found to be dying?

- Time of year
- Key priorities
- Spiritual care issues are so easily neglected and forgotten. Including the opportunity to think about God.

BGS EOLC 2018

## Theresa May

- Working with partners across ....to ensure
  - More people than ever before receive a diagnosis
  - Earlier diagnoses
  - We now have 2.5million dementia friends
- So its an important and substantial a political target.





- 66.7% of >65 people with dementia to have a diagnosis coded in GP systems.
- Failure to achieve this means that CCGs will lose money.
- National performance on this is around 68%. Best in Manchester, worst in Wessex

## Dementia

65+ estimated diagnosis rate

NHS  
Digital

Select period using the drop-down

31 January 2018

Not everyone with dementia has a formal diagnosis.  
Here we compare the number of people thought to have dementia with the number of people diagnosed with dementia, aged 65 and over.

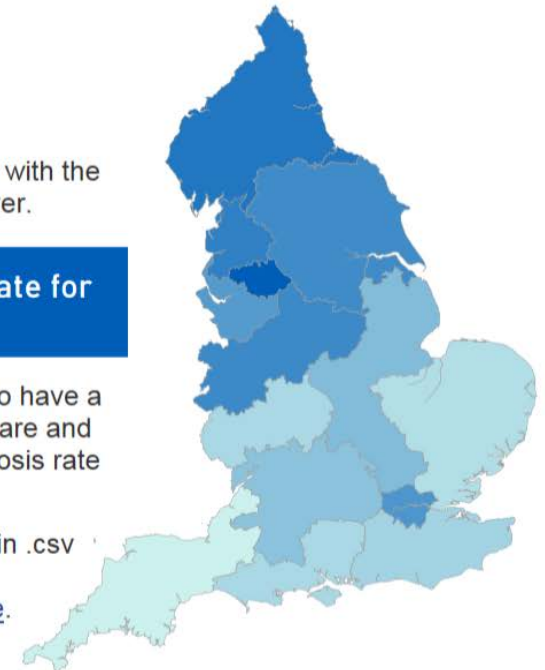
**As of January 2018, the national dementia diagnosis rate for people aged 65+ is estimated to be 67.9%**

NHS England's ambition is for two thirds of people with dementia to have a formal diagnosis, to ensure they have access to the appropriate care and support. Hover over the map on the right to find out how the diagnosis rate varies across the country.

To access the related publication, including the underlying data in .csv format, please click [here](#).

To return to the GP Data Hub homepage, please click [here](#).

Use the arrows below to navigate to the CCG-level summary:



### Performance management graphs!

- Here is my district!
- We have had a task and finish group
- Project team
- Visits to GP surgeries (which are excellent and very worthwhile)



drop-down



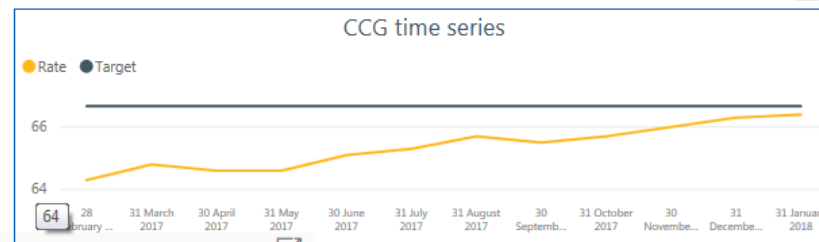
(2) Select CCG using the drop-down

NHS Bromley CCG



Estimated diagnosis rate ages 65+

**NHS BROMLEY CCG: 66.4% (neither significantly higher nor lower than 66.7% benchmark)**



DCO and STP comparison



95% confidence limits

**59.4% - 72.4%**

People diagnosed with dementia ages 65+

**2,723**

People estimated to have dementia ages 65+

**4,101**



## Others struggling a wee bit more!

- And well below that 66.7% target

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## Caution: A target is not a measure

- **Goodhart's law** ..... "When a measure becomes a target, it ceases to be a good measure."<sup>[1]</sup> This follows from individuals trying to anticipate the effect of a policy and then taking actions which alter its outcome.
- Goodhart first advanced the point in a 1975 paper, which later became used popularly to criticize the United Kingdom government of Margaret Thatcher for trying to conduct monetary policy on the basis of targets for broad and narrow money.
- His original formulation was: *"Any observed statistical regularity will tend to collapse once pressure is placed upon it for control purposes."*

## So why on earth would we want to code dementia ?

- Dementia makes a huge difference to outcomes
  - LOS
  - Complications
  - Death
  - Placement
  - Bed blocking
  - Poor care
- Better care may result from better awareness of the challenges faced by people with dementia
- And GPs do get the summary diagnosis codes on the front screen of each person they see

## Dementia and frailty

- Correlated
- Dementia an integral part of frailty
- Outcomes of frailty again profoundly influenced by presence and severity of dementia
- Dementia far more powerful than frailty in terms of predicting hospital discharge into residential care

## Money!

- Multiple opportunities to save money across frailty and geriatric services through joined up care

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## Signs and symptoms of distress in dementia

- Anger/ Frustration
- Aggression/Agitation
- Fear/ Anxiety
- Tearfulness/ misery
- Pain when still
- Discomfort on moving
- Restlessness
- Insomnia
- Calling out/ vocalisation
- Wandering
- Autonomic arousal, sweating, tachycardia, hypertension



**All these signs may reflect mental or physical pain and all indicate an attempt to diagnose the underlying cause of distress.**



# Diagnosing Underlying causes of severe distress

- Depression
- Psychosis
- Pain
- Poor understanding,
- Fear and anxiety
- Insomnia
- Hunger and diet
- Boredom, isolation and spiritual care
- Poor Environments including poor staff practices etc

May not be in order of prevalence.. But we do strongly feel that to leave depression (which affects 30% +) and psychosis (?20 – 50%) which is also very common as the last things to treat after trying all else may be a severe error that leave severe distress untreated.



- The same lady as the previous slide, but two years later after appropriate treatment.

### Before and after distress

- This lady with severe dementia was very distressed, but after appropriate care and support as well as going home from a nursing home did well. Her husband asked that her photographs to be shown so that others could understand the importance of reducing distress and increasing comfort. The point is that with good care, people can do very well



## Who does this work?

- 4000 people with dementia in Bromley
- 2000 people with moderate to severe frailty
- As well as the current Specialist Palliative Care population
- Specialist palliative care ?
- And geriatricians
- And old age psych
- And GPs
- And matrons
- And social care
- Etc etc

- A sign of dementia
- Delirium in 17.9% of Older patients
  - At 3/12
    - 6% persistent delirium
    - 17% MCI
    - 57% dementia
    - 38% had previously undiagnosed cognitive impairment

### Anyone with delirium needs

- appropriate additional care planning around discharge
- And ?an outcome assessment for dementia at 6-8 weeks



**Undiagnosed long-term cognitive impairment in acutely hospitalised older medical patients with delirium: a prospective cohort study** FREE  
Thomas A. Jackson, Alasdair M. J. MacLulich, John R. F. Gladman, Janet M. Lord, Bart Sheehan  
Age and Ageing, Volume 45, Issue 4, 1 July 2016, Pages 493–499,  
<https://doi.org/10.1093/ageing/afw064>  
Published: 13 April 2016 **Article history** ▼

## RAID teams

- Hospital MH liaison teams built upon the evidence of RAID
  - Showed large cost savings and benefits for adult mental health by having a well staffed MDT working in the acute hospital
  - Key outcomes
    - Early assessment and management in A+E (mainly for younger adults and acute psychiatry)
    - Response on wards within 24 hours for older people with dementia, contributing to diagnosis, care planning and discharge, shortening LoS etc etc
- Many such teams around the country?
- How is it going?

## Results of the RAID study

- **Results**

- The main direct effect of the RAID model was on time to readmission:

- The rate of readmission in the RAID group was 4 for every 100 patients
- While in the pre-RAID group it was 15 for every 100
- Including the RAID-influence group, the total reduction in readmissions is estimated to be 1,800 over 12 months. This equates to a saving of 8,100 bed-days per year

- There is also a strong indirect effect resulting from the broader influence on those not referred to the service, in the form of reduced lengths of stay:

- The RAID-influence group demonstrated an average length of stay 3.2 days shorter than that of the pre-RAID group. This corresponds to a total saving of **13,935 bed-days per year**
- All in all, the RAID model is **estimated to save between 43 and 64 beds per day, which is equivalent to 2-3 wards**
- **Most of the savings were accrued by geriatric wards**



## Benefits

- ? Might be overestimated
- But liaison for OP does work and does help.
  - Shortening length of stay
  - Improving care
  - Very appreciated by medics and families alike
- Note that it is important to have an adequate sized team or you may find the benefits for older people are constrained by the urgency of acute younger adults in crisis. It is also important to have the right skills for older people in the team.

## Frailty services

- Now set up and established in GP clusters across the country
- Enabling better care across systems
- With geriatricians in community ward rounds, access to scans, bloods etc
- Able to diagnose dementia
- Able also to access social care

## Things you can do!

- Diagnose dementia and put it in the discharge summary
- Care plan discharges for dementia
- Arrange follow up and outcome assessment for delirium

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## Background

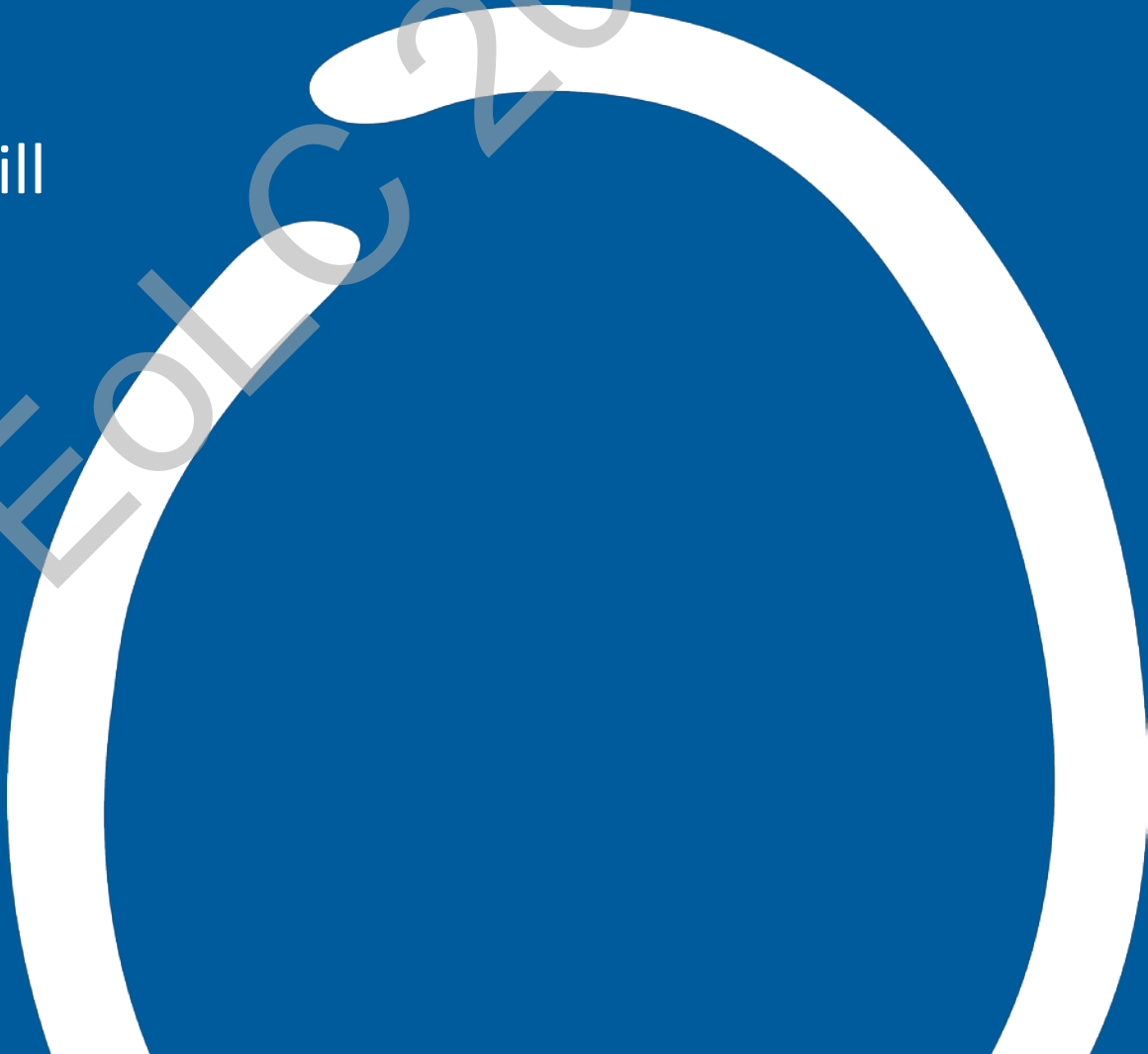
- Acute hospital care is under huge pressure with large overspends on unplanned emergency admissions.
- Audit of emergency admissions showed that:
  - 75% of patients are >65y, 90% of those in intermediate care are > 75y
  - 25% of admissions may be avoidable with better care in the community.
- Most people with dementia go through A+E and acute medical assessment units in the last 6 months of life. We enable avoidance of this.
- Caring for people at home and avoiding use of care homes saves money. NCPC (2009) estimated that care at home cost £17,075 less in the last 6 months of life than care in a care home.
- Home care of dementia until death is a rare event, poorly understood and not encouraged by statutory services.






## The Story of Jack and Jill

*Improving lives*







A graphic featuring a blue hospital sign with the word 'HOSPITAL' and a large 'H', a magnifying glass, and a globe.



MEDICATION	TIME	1	2	3	4	5	6	7

## The Oxleas Advanced Dementia Service

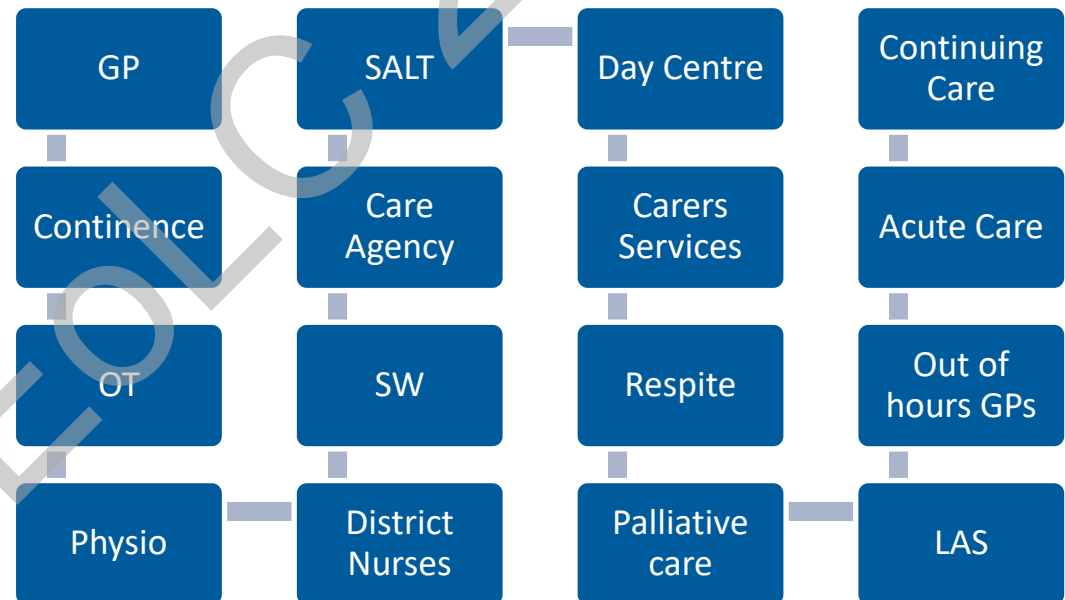
**We believe that anyone cared for at home with advanced dementia deserves care coordination and on-going support.**

Our service combines mental and physical health expertise, to look competently after patients with advanced dementia living at home and:

- Comprehensively assess and plan ahead
- Care co-ordinate
- Respond quickly when needs are changing
- Establish a palliative care framework with a focus on maximising quality of life, help avoid or shorten unnecessary and traumatic hospital admissions, treatments and investigations and replace them with home care whenever possible
- Offer excellent care towards the end of life
- Relieve the carer from having to navigate alone within a complex care system while grieving.



## Integrated care plan and care co-ordination



"Without this service we'd be lost. Mom would be in a care home and dad faded away by now. We had a better year this year than we had in a long time."

### Key effects

- Enabling people with dementia to live well at home until they die
- Integrated care plan
- Building resilience among carers
- With excellent feedback
- Delivering a holistic care assessment and a personalised care plan
- Giving dedicated care co-ordination
- Giving rapid access to advice and support from a multidisciplinary team

### Financial

- Hospital admission in last year of life 25% not 80%
- Large savings on care home and PCT nursing care contribution funding
- Saved £2.5million on 100 cases using cautious figures



To Adrian with love from Grace

## Key benefits for patients, carers and commissioning bodies



- ✓ Avoided care home admission and reduced hospital admission



- ✓ Achieved better access to diagnosis, care, treatment, support and information



- ✓ Improve domiciliary care and facilitate use of new technologies



- ✓ Used integrated support and care co-ordination to enable people with dementia to live well at home until they die



- ✓ We supported the whole family and have excellent carer satisfaction reports



- ✓ Through avoiding admissions and straightening the care pathway we offer a cost effective service

## How we build resilience?

- By providing someone who is a single source of support and advice
- Competence in
  - Managing distress in dementia
  - Psychological complications of dementia
  - Managing or accessing excellent care of physical crisis at home
  - Physical management of advance disability
  - Commissioning social service support
  - Commissioning physical aids (beds, hoist, continence, mobility aids etc
  - Bring in appropriate GP and district nurse input
  - Access to OT
  - Carer support ad assessment
- Being responsive, being willing,
- Bringing hope





## Example Mrs A

- Mrs. A is a lady with:
  - advanced dementia, epilepsy, myoclonic jerks, trigeminal neuralgia and huge restlessness and agitation.
  - a family who wanted to keep her at home but felt that it would be impossible
- Interventions:
  - Seen regularly, family supported, problems discussed.
  - Medication modified through the progression of illness
- Outcome
  - able to stay at home and doing really well

## Example Mrs A (continued)

- Crisis: Episode of choking when swallowing!
  - Ambulance called, arrived but family declined admission
  - GP called (got there 7 hours later)
  - Immediate telephone support from us, discussion of options and visit that evening
  - Hospital admission was avoided
- With clear quality, emotional and financial gains



### Is that too much to ask?

- We now know that
  - The model which first worked with a few patients and one key person ....
  - Also works with other dedicated, caring staff
  - Has also been developed in Westminster and Reading and elsewhere
  - And it is rewarding for staff who “get it”
  - And there is very positive feedback from carers who say that our support was/is absolutely central to success.



“The nurses and specialist all said they were very worried about the plan to go home and thought it a bad idea. Her husband insisted, and after discussion it was agreed that this could be tried. Wonderfully, she did well. ”

**TheKingsFund** Co-ordinated care for people with complex chronic conditions

**Authors**  
Lara Sonola  
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**Oxleas Advanced Dementia Service**  
Supporting carers and building resilience

### GP Masterclass events



**Oxleas NHS**

**Oxleas Dementia Strategy**  
2013 - 2016

Improving lives  
oxleas.nhs.uk

ARTICLE

**Palliative and end-of-life care of dementia at home is feasible and rewarding**

Results from the 'Hope for Home' study

**ADRIAN TRELOAR** Oxleas NHS Trust and the Institute of Psychiatry, UK  
**MONICA CRUGEL** Memorial Hospital, UK  
**DIMITRIOS ADAMIS** Memorial Hospital, UK

**dementia**  
http://dem.sagepub.com  
VOL 8(3) 335-347

**2009 Recognition Awards - Excellence**

**Winner**  
**Greenwich Advanced Dementia Service**

### Staff recognition awards 2013 Partnership: Runner up





Success; living well, dying with family at home



## Does better quality save money?

- Not always, but ...
- Yes; often!

My favoured delusion =

- Yes always
- Or at least if it doesn't I don't care  
'because I want to do good care!

### Excellent home care is possible

- Managing distress is central (which is a far more important concept for the patient than “behaviours that challenge” as the latter is not patient centred).
- Look underneath it for the cause and treat the underlying cause according to good practice advice
- Prognosis is not the key to need
- Good services save money and provide better quality care.



## The Greenwich Advanced Dementia Service (GADS)

- Cared for >200 people so far
- Now carries a caseload of 50
- The service is very successful and feedback is very positive
- Around 75% die at home
- A small number in hospital for a few days prior to death.
- No Out of Hours team
- No funding





### Current home support poorly organised and far from ideal

- *'GP was very good when could get to surgery but when it came to visits was a problem. Rarely made house calls except in the last few weeks. Probably pressure in the surgery. It would have been useful even as a routine thing for 5 minutes, that would have made a difference to mum. Just that short visit would have been helpful.'*
- *'GP never came out.'*



Quotes and data are from GADS audit

## And all components of care may be lacking

- *‘Until she actually got attendance allowance no-one wanted to give any help at all. Until she was actually registered as having attendance allowance there was actually a blank wall.’*
- *‘With social services, as K was less than 65 she did not fit into a box. So she was not helped. Told not eligible for direct payments.’*

Quotes and data are from GADS audit

# Equipment is essential



- ‘We only got the pads as we knew who to contact ordinary people don’t know and just have to wait. Some don’t even know they can have them. The home care team would have left Nobby as he would have said “go away”. It needs special skills to engage and clients don’t mean to say “go away”.’*

Quotes and data are from GADS audit

## Support is hugely valued

- *'He looked forward to the psychiatrist coming... you would call in sit there holding his hand. When he could talk he did like a good talk. Just popping in was brilliant, his face would light up.'*
- *'Psych was the only one who kept in contact and visited when he didn't have to.'*
  - *But note that this reflects that person having a real care coordination role*

Quotes and data are from GADS audit

### How much have we saved

- 100 cases
- 75% admission avoidance
- Average time on caseload 483 days
- Conservative estimates suggest
- £2.47 million saved

time in H4H care	Time between leaving home and death	admissions in last year of life	Saving of H4H to PCT (£100 per week)	Saving of H4H to SS (200 per week)	savings on admissions to	total savings	cu
<b>482.73</b>	<b>Total</b>		<b>778570</b>	<b>1557139</b>	<b>141000</b>	<b>2476709</b>	
163.00	0	0	2329	4657	3000		
492.87	0	0	7041	14082	3000		
289.00	0	0	4129	8257	3000		
81.00	0	0	1157	2314	3000		
167.00	0	1	2386	4771	0		
196.00	0	0	2800	5600	3000		
42.00	0	0	600	1200	3000		
547.00	33	1	7814	15629	0		
13.00	25	1	186	371	0		
348.00	0	0	4971	9943	3000		
187.00	0	0	2671	5343	3000		
229.00	0	0	3271	6543	3000		
518.00	13	1	7371	14743	0		
54.00	6	1	771	1543	0		
601.00	0	0	8586	17171	3000		
373.00	0	0	5329	10657	3000		
258.00	0	1	3686	7371	0		
290.00	0	0			3000		

## Savings per year (2009)

- Caseload of 25
- Estimate of 17 hospital admissions avoided
- 6205 days of care (i.e. **17 years** of care home costs avoidance!)
- Annual saving = **£225,556**
- **And the Kings fund said**
- The economic benefits are easy to see but hard to prove. Like a precious jewel a sea of mud!



- Is this a giant Ponzi scheme built upon optimism and hard to demonstrated benefits
- Are not the financial savings already spent three times over and also overestimated?
- Is any of it true?
- What can we access at 2am?

- Well....
- Firstly access to advanced dementia care came from Older persons liaison assessment as long as the two services talk together
- Secondly, the amazingly positive feedback gives a clue
- Thirdly, all systems disintegrate into component parts if they are not held together
- AND perhaps the glue of Primary Care no longer works as GPs are less involved in home visits and home care than they were
- THEREFORE we have to carry on working to deliver joined up care, and forming our services so that the hospital is as permeable as possible,
  - able to discharge to social care
  - And able to admit from social care etc etc



## Or putting that another way

- The challenges of 2018 modern medicine are partly because we have been so successful with hypertension, weight, exercise and smoking and lipid care etc.
- And also because medicine has become so clever
- And pathways have helped
- But also because we (as a profession and as a society) have allowed our excellence to sit within pockets that become isolated etc etc
- The challenges and the current crisis have happened on our watch.
- And in all these settings, there is a real need to do the geriatric thing and have a specialist service for specialist need . And not generic services for specialist geriatric need.
- If we do not do that, people with dementia will truly suffer.

## The success of what you do

- Living well with frailty and dementia
- Remember that you often manage extraordinary things by the care you provide and the changes you make
- But especially hospital doctors and nurses do not always get to see that.
- Living and dying well with dementia and frailty include good care, support and also some extraordinary
- On a trip to Bluewater, here is an example of an extraordinary outcome. ....