NHS RightCare scenario:
Getting the dementia pathway right

Tom and Barbara's story: Dementia

Appendix 1: Summary slide pack

April 2017

Tom’s story

This is the story of Tom’s experience of a dementia care pathway, and how it could have been so much better

1

In this scenario we examine a dementia care pathway, comparing a sub-optimal but typical scenario against an ideal pathway.

2

At each stage we have modelled the costs of care, both financial to the commissioner, and also the impact on the person and their family’s outcomes and experience.

3

This document is intended to help commissioners and providers to understand the implications – both in terms of quality of life and costs – of shifting the care pathway

4

It shows how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway.

Tom and the sub-optimal pathway (1)

- **Tom** (a retired engineer) lives with his wife Barbara and is **77 years old when he first starts to experience symptoms**
- Tom is **reluctant to go to the GP**. Barbara adjusts and keeps on keeping on, but tension is building (e.g. Tom was lost for several hours whilst walking)
- It is not until the **fourth year** (after symptoms started) that Tom becomes **violent and entered the secondary care system**
- He is **admitted to hospital for five weeks**; he is moved frequently and needs two security guards to keep him in bed. Barbara is not allowed to stay with him and can only visit during regular visiting hours. In a period of confusion, Tom falls out of bed and bruises his leg quite seriously
- Given Tom's deterioration it is now already **too late for him to be able to grant Power Of Attorney**
- In year 6, (aged 82) Tom is admitted to hospital again after significant confused episode and is found to have a **severe infection from tooth decay**
- **Barbara** is undertaking a super human effort and **is increasingly isolated and** exhausted
- By year 9, Tom is reluctant have help with feeding and this results in **significant loss of weight** and admission to hospital with pneumonia
- Tom is **discharged to a care home** where he dies after three months aged 85.

Tom and the sub-optimal pathway (2)

No prevention

- Reactive
- Limited education
- No third sector involvement

No risk profiling and identification

Pillar to post

- Traditional treatment
- Several wards
- Too much time in a secondary care bed.

Inappropriate acute care

Too late

- Damage done
- Too much reliance on acute care

Insufficient home care support for carer

Statistics

- Over a quarter of hospital beds in the UK are currently occupied by people with dementia
- One third of people with dementia who go into hospital for an unrelated condition NEVER return to their own homes
- 47% of people with dementia who go into hospital are physically less well when they leave than when they went in
- 54% of people with dementia who go into hospital are mentally less well when they leave than when they went in

Alzheimer's Society 2009 report - Counting the Cost

10 days in a hospital bed (acute or community) leads to the equivalent of 10 years ageing in the muscles of people over 80

Gill et al (2004) studied the association between bedrest and functional decline over 18 months. They found a relationship between the amount of time spent in bed rest and the magnitude of functional decline in instrumental activities of daily living, mobility, physical activity and social activity.

Kortebein P, Symons TB, Ferrando A et al. Functional impact of 10 days of bed rest in healthy older adults. J Gerontal A Biol Sci Med Sci. 2008;63:1076-1081

Questions for GPs and commissioners

NHS RightCare

In the local population, who has overall responsibility for:

1. Promoting dementia as a condition for which targeted interventions (including prevention) must be planned and delivered?
2. Identifying individuals living with dementia?
3. Planning care models to address key stages of dementia (pre/early, moderate or severe)?
4. Identifying and reporting on measurable positive and negative dementia associated outcomes?
5. Quality assurance and value for money in addressing the needs of those with dementia?
6. Quality assurance and value for money of continence care?
7. How do we do the right thing for the patient and at the same time recognise that costs shift from health to social care?
8. Has any engagement activity taken place with patients with regards to dementia care?

Tom and the optimal pathway (1)

- Tom, **aged 77**, goes to his GP with Barbara who recommends he **has a memory assessment** with someone from the memory clinic
- **Three weeks after** seeing the GP Tom is assessed by someone from the memory clinic at the GP practice
- Tom is told he is likely to have dementia, but a brain scan will confirm this.
- **Tom receives a diagnosis** and is prescribed an acetylcholinesterase inhibitor. He is also **introduced to the local dementia advisor**. A care plan is developed that includes a series of local post diagnostic support activities
- In year 2, Tom sees his GP and it is considered that he most likely has **a urinary tract infection** and is prescribed antibiotics (**avoiding secondary care**)
- The Dementia advisor also offers **high quality support** (a lifeline to Barbara) including guidance around Power of Attorney
- Tom gets involved in lots of post diagnostic support groups including a walking group. **Later he has a fall** and is taken to A&E – but it's only a bruise, **good healthcare communication results in a very short stay**
- Tom and Barbara maintain **active lives together** until year 8, with also **Barbara receiving valuable respite**
- In year 10, Tom is admitted to a care home as his needs can no longer be met in the home with Barbara as his primary carer. (**10 good years together post diagnosis**).

Tom and the optimal pathway (2)

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Prevention focus	Fast	Appropriate
• Proactive • Educational • Third sector involvement	• Bespoke treatment • Minimum time in bed / secondary care • Greater understanding of need	• Support mechanisms in place • Trusted system • Happier and healthier experience
Early risk awareness and identification	Great acute care	Great home care support

Financial information (1)

Analysis by provider	Sub-optimal	Optimal
Acute	£17,428	£600
Ambulance service	£233	£233
Care Home	£7,670	£7,670
Primary care	£7,119	£8,136
Third Sector	£0	£1,675
Grand total	**£32,450**	**£18,315**

Not only is Tom's (and his wife's) health and quality of life significantly better in the optimal scenario, but the costs to the health economy are reduced by 43%*. The impact is significant on outcomes, quality and finance.

*Costs calculated as at 15/16 prices.

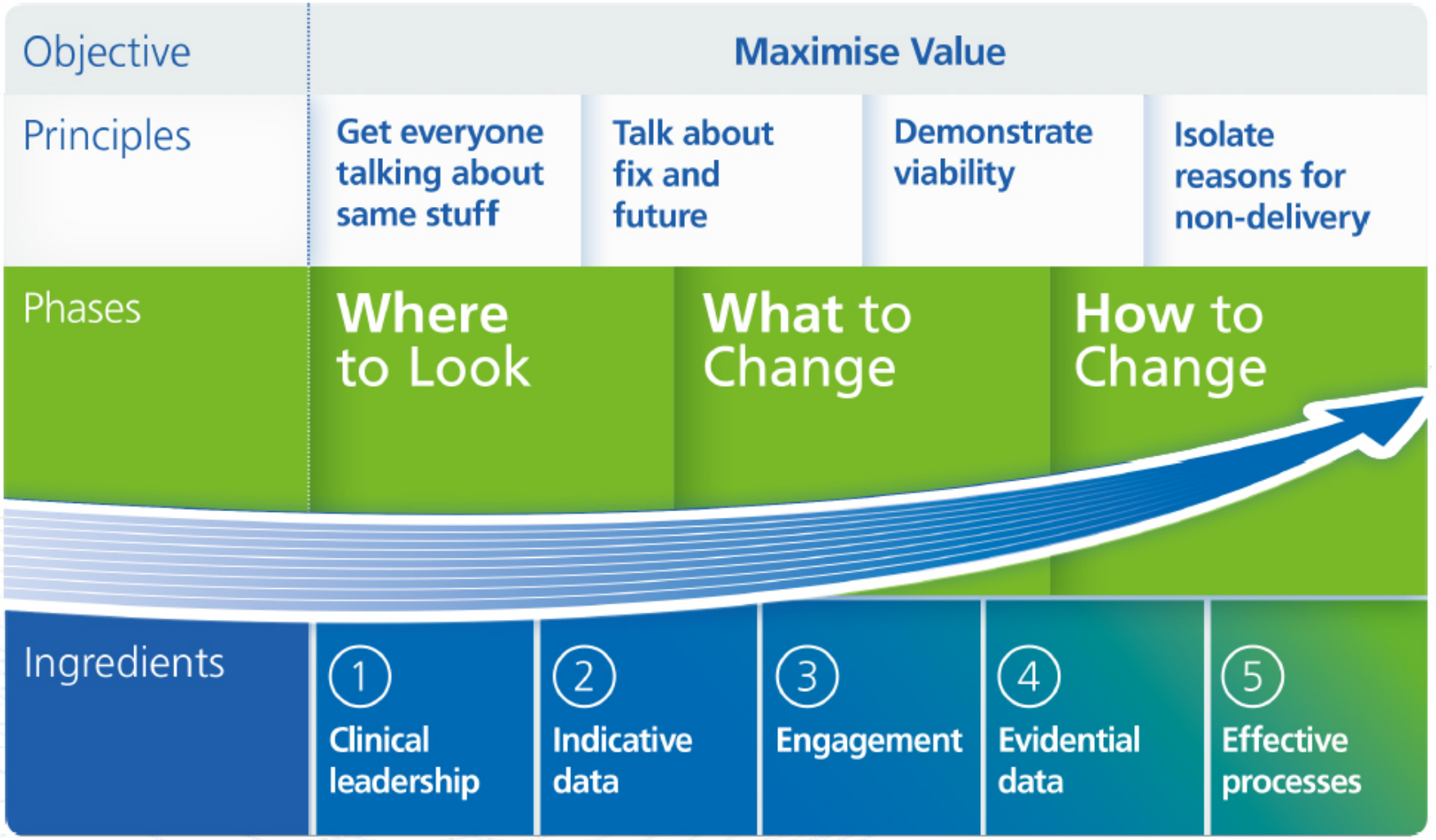
Financial information (2)

Analysis by cost category	Sub-optimal	Optimal
Primary care management	£7,075	£8,136
Urgent and Emergency Care	£461	£233
Secondary Care Management	£17,200	£600
Intermediate Care	£7,670	£7,670
Community Care	£0	£1,675
Grand total	**£32,450**	**£18,315**

This scenario is using a fictional patient, Tom. It is intended to help commissioners and providers understand the implications (both in terms of quality of life and financial costs) of shifting the dementia care pathway.

- **Primary care** expenditure is 15% more in the optimal scenario. Most of this investment is centred on: a) a dedicated dementia advisor (£7.4k) and b) early diagnosis and earlier prescriptions for inhibitor drugs. The % increase is relatively small because there are significant cost savings associated with incontinence products (£6.9k variance between the two scenarios).
- **Secondary care** expenditure is radically different, ranging from three hospital admissions totalling 43 days as an inpatient, compared to one day's stay in the optimal scenario (£17k vs £1k)
- **The third sector** also makes a significant contribution in the optimal case with the provision of the 'singing for the brain' programme (£1.7k)

The NHS RightCare approach



Further information

For more information about Tom's journey, NHS RightCare or long term conditions you can:

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