



Improving End of Life Care for patients with dementia at RLH

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Background

- A number of referrals for patients with dementia admitted to RLH and subsequently died whose families seemed under prepared and anxious which impacted on the quality of care the medical team were able to provide
- It was easy to see in hindsight that this was the situation but if we could work better with patients and families to plan ahead and understand what was important to patients, and prepare them and their families, we could make the experience more bearable for them
- Aim was to help staff to identify that death is approaching and to improve their confidence in initiating appropriate discussions
- As we thought about the necessary steps we realized that advance planning and preparation can ease this process considerably for patients and their families

Improving end-of-life care for patients with dementia





PDSA cycles

- Hypothesis is that providing the opportunity to think ahead with professional support improves patient and carer satisfaction
- Developed a questionnaire to measure patient/carer satisfaction
- Decided to use this questionnaire to understand better what patient and carer priorities were and gather quality improvement ideas
- Developed a diagnostic discussion checklist



Sequence of PDSA's

Cycle 2: Diagnostic discussion checklist

Cycle 1: : Patient/family questionnaire



- Planning database of patients newly diagnosed with dementia
- Planning process measures on checklist
- Adding Lickert scale to Patient/family questionnaire
- Outcome measure on whether possibility of 'thinking ahead' has been raised



Learning

• Developing a feedback questionnaire is more difficult than you might think!

We need to improve the quality of our diagnostic discussions, to ensure a carer is present for this and to consider providing written personalized feedback

- We need to take advantage of the links we have with the Alzheimer's society and the excellent support they provide
- Carers we had spoken to would appreciate help thinking ahead
- Patients that we have interviewed so far did not engage with the feedback questionnaire
- It has been an excellent opportunity to work across professional and specialty boundaries – we have benefitted enormously from pooling our areas of expertise
- Patient and carer feedback is a very powerful motivator for change



What next?

- Trial the diagnostic check list and monitor whether this improves patient/carer satisfaction
- Post-diagnosis, post-discharge clinic to facilitate Alzheimer's society involvement
- Training for team and acute trust staff in initiating conversations about thinking ahead
- Information toolkit for staff on end of life care in dementia
- Gathering information about what support is available in the community for care planning and how care planning information is recorded - what we provide needs to be well integrated with care provided by other parts of health and social care services
- We have lots more to do
- We need to look at other groups of dementia patients those already diagnosed and those approaching the end of life