

## Dementia Select Committee

### Terms of Reference

1. To examine issues around the '9 Steps' of 'Quality Outcomes' for people with dementia and their carers in Kent.

**The 9 Steps<sup>1</sup>:** Draft synthesis of outcomes desired by people with dementia and their carers

By 2014, all people living with dementia in England should be able to say:

I was diagnosed early  
I understand, so I make good decisions and provide for future decision making  
I get the treatment and support which are best for my dementia, and my life  
Those around me and looking after me are well supported  
I am treated with dignity and respect  
I know what I can do to help myself and who else can help me  
I can enjoy life  
I feel part of a community and I'm inspired to give something back  
I am confident my end of life wishes will be respected. I can expect a good death.

2. To identify good practice and innovation in Kent and elsewhere, that could contribute to achievement of the '9 steps'.

3. To identify factors militating against achievement of the '9 steps' and make recommendations for improvements.

### New Draft Scope

*(Carers contributing to the review will have the opportunity to comment on the scope in February/early March)*

Engage with people with dementia and carers and with older people through district forums.

*Address:*

*Stigma* – what are the effects/impacts and how can it be reduced? What can be done to promote awareness among younger people and encourage inter-generational support? What do older people think about the stigma around dementia and how to address it? What groups of people might suffer additional stigma for cultural/other reasons and how could this be addressed?

*Awareness-raising among professionals* – what training is currently undertaken by professionals in different settings? Is it compulsory/linked to progression? What accreditation is in place? How successful is the training that takes place?

---

<sup>1</sup> DH (2009) Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy

*Inclusiveness of training, care and support* – how well are cultural needs of ethnic minorities understood and catered for? What are the issues affecting people with learning difficulties that have dementia? Does having a particular sexual orientation mean that different factors should be taken into account? What issues affect people with dementia who have co-morbidities in relation to accessing support? What services and support are there for people with early onset dementia?

*Early diagnosis* - what is already known about factors preventing early diagnosis? What is happening across Kent and what best practice has been identified? What are the issues for GPs and other professionals? How could things be done differently? Is diagnosis always necessary? What are the processes for referral?

*Post-diagnosis support* - how are people with dementia supported post-diagnosis? What services are already in place? What best practice examples are there? Where are the gaps in the provision of support? How can the role of the voluntary sector be maximised?

*Carers* – what can carers expect as they take on the caring role? How is the partnership between a carer/carers and the person they care for supported?

*Technology* - what is the role of technology including Telecare in maintaining peoples' independence and supporting carers? What ethical issues need to be considered?

*Information, advice and guidance* - can people with dementia (including those who may not be diagnosed) and carers access the information they need including signposting to support, at the right time, in the right places and in the right formats?

*Decision-making* - Mental capacity: how and by whom is this assessed – what are the issues? What are the implications of Lasting Power of Attorney and how are people enabled to make decisions about their future? What are the issues around deprivation of liberty and how is this applied?

*Personalisation* – What are the issues around personalised budgets and direct payments for people with dementia? What are the issues for carers?

*Person-centred care* – how can joint commissioning contribute to person centred care? What opportunities are there for pooling budgets for care and support from different sources in order to provide more personalised services?

## **Exclusions**

It is proposed 'end of life care', other than from the perspective of decision-making, is not included, it being more suited to investigation by a separate, full and focussed select committee review.