

9<sup>th</sup> November 2009

Ravinder Carothers  
Mental Health Delivery and Services Unit  
Room 3. ER  
St Andrews House  
Regent Road  
Edinburgh EH1 3DG

Dear Ravinder

**The National Dialogue on Dementia: Dementia Strategy Consultation Paper**

Shared Care Scotland (SCS) is a national voluntary organisation which promotes the importance of short breaks and respite care across all service groups. In recent years dementia has featured increasingly in our activity and we have benefitted in our understanding of the needs this condition generates by input from people with a diagnosis of dementia and their carers.

SCS operates OSBIS (On-line Short Breaks Information Service) which includes in its database details of short break/ respite opportunities available to people with dementia and their carers.

We commend the actions which have been initiated by the Scottish Government to respond to the needs of the growing numbers of people in Scotland affected by dementia, and we are pleased to see the statement in the Ministerial Foreword that proper attention will be paid to the resources required *'even within the current challenging financial circumstances'*.

We welcome the recognition in the introduction that for each person with dementia, an average of three other people are directly affected. This highlights the importance of ensuring that the Dementia Strategy to be published next year takes full account of the parallel work taking place to develop a national strategy to support unpaid carers. We note that carers are represented in each of the workstreams. We hope that, in addition, the Dementia Forum and/ or the Dementia Strategy Management Group will consult directly with those involved on the Carers' Strategy to ensure that everything possible is done to help carers support people with dementia in their own homes for as long as possible.

The only explicit reference to unpaid carers in the remits of the Workstreams is in Workstream 2, where information and support to carers is mentioned in the context of early diagnosis and response to dementia. We consider that the needs of carers should be acknowledged elsewhere in the Workstreams, particularly in respect of:

- Responding effectively to challenging behaviour (Workstream 1)
- Managing transitions (Workstream 2)
- Considering the standards of service delivery in place for those with dementia and their carers (Workstream 4)

We respond to your five questions as follows:

#### Question 1

See suggested additional work on carer issues. We would also like to suggest that Workstreams 2, 4 and 5 should incorporate in their work consideration of the benefits of providing regular and appropriate short breaks/ respite in care plans, ICPs and carer assessments.

#### Question 2

In earlier documents about dementia, the Scottish Government has made reference to cognitive, as opposed to pharmaceutical, interventions. There is limited reference here to the role counselling can play both for people with a diagnosis and for carers and family members. There is also no explicit reference in the description of the remit of Workstream 3, to non-NHS supports through social and recreational services. It is not clear if this is indicative of a medical bias which might need to be redressed.

#### Question 3

The work outlined covers a range of priorities from early diagnosis to palliative care. This broad approach is commended. The provision of appropriate services for people who reach the later stages of the condition, and for carers faced with challenging behaviour and the realisation that they can no longer cope, is particularly crucial, as we are sure feedback from Alzheimer Scotland's 24 hour Dementia Helpline will confirm.

#### Question 4

It will be important to identify milestones for measuring progress on a year by year basis, perhaps with a vision of where the Scottish Government hopes to be by 2020.

#### Question 5

Shared Care Scotland is well placed to help in raising the profile of short breaks and respite care by further development of OSBIS as a reference tool for families and service providers and through our practitioner support networks. It can also play a part in evaluating the outcomes of planned delivery of flexible and person-centred short breaks/ respite care for people affected by dementia.

*Shared Care Scotland  
Response to Dementia Strategy Consultation Paper*

Thank you for the opportunity to contribute to this important piece of work and we look forward to reading contributions from other individuals and organisations in due course.

Yours faithfully

Don Williamson  
**Chief Executive**  
**Shared Care Scotland**