

# Data supplement

## The MARQUE project – In-depth interview schedule (Questions only)

### Managing Agitation and Raising QQuality of Life: Stream 4: Qualitative study of people with dementia and agitation and their family carers living in domestic environments

#### SECTION 1

##### General questions about the person with dementia and the carer

- i. **Looking back, when did you first notice the signs of the memory problems? So, how were things ok before that?**
  - Ask how long they have been caring for their relative? Have they always lived together or when did they move in?
  - Determine the length of time the participant has spent caring for their relative and acknowledge this.
- ii. **How have you found the experience of caring for .....?**  
Have there been times that were difficult when you were caring for your relative/friend?
- iii. **Was there any help or support available to you at those times?**  
(ask as a general question and determine what support they have e.g. network of family and friends, professional support, voluntary sector support, individualised or group etc).

#### SECTION 2

This section is focussed on discussing episodes of agitation in dementia in-depth.

- i. **Could you tell me a bit/ a bit more about situations related to your relative/friend's symptoms of agitation and dementia?**
- ii. **When did your relative/friend start to show symptoms of agitation? How did this affect your experience as a carer**
  - Does anything happening in particular/ particular events in the period leading up to the agitated behaviour? Were there any triggers to the incidents of agitated behaviour?
  - (It would be good to discuss whether there were any warning signs that the carer was picking up at the time of the incident or whether it was more apparent in hindsight)
  - (Things to look out for: lack of cooperation with personal care, repetitive vocalisations, restlessness, verbal abuse, aggression, combativeness, shouting, hyperactivity and disinhibition).
- iii. **What symptoms of agitation did you observe?**
  - How often does your relative/friend experience agitation? What do you think causes the symptoms of agitation in dementia to occur?
- iv. **What was it like for you? What was it like for your relative/friend?**

### **SECTION 3**

**This section focuses on finding out from the carer about how they dealt with any episodes of agitated behaviour.**

- i. **Were/ are there any particular ways you dealt/ deal with your experiences of agitated behaviour then/ now?**
  - What did/do you do to cope with the symptoms of agitation? Which symptoms of agitation do you find most difficult to cope with in dementia?
  - Did you find 'doing things' such as activities or exercise helped as a distraction? Have calming activities like listening to music, relaxation or massage helped? Does your relative respond well to physical comfort and reassuring touch?
  - What did/do you do that helped the situation?
  - What made things worse?
  - Was there a time when you felt like you just could not cope any longer?
  - A time when there was a risk of a breakdown in care?
  - What did you do to help yourself cope with the situation? Do you ever use prayer or meditation to help you cope? Did you have a network of friends and family to support you?
- ii. **Did you seek any help for managing the agitated behaviour?**
  - Why/ why not? How did you find the support which you received? Did you find it helped during or after the event?
  - Was it from friends or family or services or all
  - Did the support services that you received make a difference? What was it that helped? What made it worse?

#### **SECTION 4**

**This section focuses on asking the carer to reflect back on the episodes of agitated behaviour and to discuss their feelings/ thoughts in relation to their past experiences.**

**i. Looking back how do you feel about the episodes of agitated behaviour that occurred?**

- Do you think you would have done anything differently? If so, what?
- Were there any things that could have helped that were not available at that time e.g. information?
- How might you deal with something like that again in the future?

**ii. Do you have any advice that you could give to people going through the same difficulties?**

- How do you feel talking about it today?
- How does it affect your relationship with your relative/friend?

**iii. Is there anything else that you want to mention about how you coped with your relative/friend's agitation?**

**THANK THE INTERVIEWEE FOR THEIR PARTICIPATION.**