

## **DREAMS START (Dementia Related Manual for Sleep; Strategies for Relatives) feasibility and pilot study: Focus group feedback on intervention manual for development**

**Introductions:** Thank you for agreeing to take part in this group. My name is.... As you know I am a researcher from xxx and I will conduct and record this focus group. Everything you say is confidential but I would like you to introduce yourselves so that the typist can identify you.

**Description of the research:** We are in the process of developing a manual which, over the next year, we are going to be testing out with people with dementia and their family carers as part of a trial. It will be delivered to individuals at home, and we hope that it will help with sleep and lead to improvement in quality of life for people with dementia and their families. The intervention will be based on what we know works from research and practice with people who do not have dementia and on our specialist research and clinical knowledge of people with dementia and their families.

Before we finalise the intervention, we want to hear your views and opinions about what we have developed, and then make further changes to the intervention manual. We are asking you because we know that you have responded to the Alzheimer's Society invitation as this is something you are interested in and probably have experience of. We want to make use of your expertise.

### **Sleep difficulties / current understandings**

*Q. Could you tell us about any sleep difficulties that your relative experiences?*

- *What do you notice happening at night and during the day?*
- *What effect do these problems have on you and your relative?*
- *How do you understand what may be causing these sleep difficulties for your relative?*
- *Which sleep difficulties do you find most difficult to manage?*
- *What has worked well in managing sleep difficulties?*
- *What have you tried?*
- *What has not worked well?*

We are particularly interested in how to make the manual practical and to fit in with peoples' lives.

**Introduce the manual:** *Show them the draft manual / structure and present an overall summary:*

- People with dementia and their families will receive their own copy of the manual to write in and keep.
- They will wear an actigraph (special watch) to see how their sleep rhythms are.
- There will be practical suggestions to try out between sessions.
- There will be one member of staff working with the person with dementia and their family.
- The manual contains information about sleep and dementia.
- Each session will include a combination of information giving, discussion, making an individualised plan with practical exercises including increasing light at particular times and increasing activity.
- There will be a relaxation exercise and people will be given a relaxation CD or MP3 files.
- Each session will be around an hour.
- The staff member delivering the intervention will be supervised by a clinical psychologist and their GP and memory service team will know that they are in the study.

The sessions of the DREAMS intervention include:

- ★ Learning about sleep and dementia
- ★ Relaxation and bedroom comfort / pre-bed & mealtime routine
- ★ Using natural light, morning wake-up light

- ★ Pleasant activities
- ★ Management of daytime naps
- ★ Relaxation, especially at night
- ★ What works? Using skills and strategies in the future

*Give them a few minutes to look through and make any general comments. These prompts are only if not already covered. (Explain that this is only a draft / outline)*

**Q. What are your initial thoughts on the manual?**

**Q. What do you think about the design of the manual?**

**Prompts:**

- How do you find the layout?
- Is it easy to read and follow, e.g. not too much text on each page / fonts / colours?
- What do you think of the pictures and images – more, less, different?
- How do you find the balance of information giving and discussion?

**Q. What do you think about the outline structure & content of the sessions?**

**Prompts:**

- Do the topics and examples fit with what your experience is or has been?
- Is there anything important that you feel is missing?
- Does the order of the sessions make sense?
- Is it pitched at the right level for a range of people?
- Is it easy to understand?
- Do the key points stand out?

**Q. Do you have any other feedback regarding layout, design, content etc?**

**Q. What do you think might make it harder for people to participate in the sessions and use the manual? (Prompt about wearing actigraph, using light box, increasing activities)**

**Q. What do you think might make it easier for people to participate in the sessions and use the manual? (Prompt about wearing actigraph, using light box, increasing activities)**

**Q. Before we finish, is there anything else you would like to mention that we have not already covered?**

**Thank you for taking part today.**

## **DREAMS START (Dementia Related Manual for Sleep; Strategies for Relatives) feasibility and pilot study: Focus group with family carers post intervention.**

**Introductions:** Thank you for agreeing to take part in this group. My name is.... As you know I am a researcher from xxx and I will conduct and record this interview. Everything you say is confidential but I would like you to introduce yourselves so that the typist can identify you.

**Description of the research:** We have now completed the feasibility and pilot study of the DREAMS:START intervention and wanted to meet with you all today to discuss our findings and any potential changes to the manual in the future. Before we begin talking we will briefly tell you about the final version of the manual we used in the study and how we delivered it and then XXX tell you about study has gone and what the people who received the intervention told us about how they found it.

Following our discussion today and based upon the findings of the study so far we will probably make further changes to the manual and how we deliver it which we will hopefully test in a randomised controlled trial in the future. Therefore we want to hear your views and opinions about what we have developed and tested and of how it could be improved before further testing.

**Revisiting the manual:** *Show them the manual used in the study and present an overall summary (present summary slides of content and process):*

- People with dementia and their families will received their own copy of the manual to write in and keep.
- They wore an actigraph (special watch) to see how their sleep rythms were
- There were practical suggestions to try out between sessions.
- There was one member of staff working with the person with dementia and their family.
- The manual contained some information about sleep in dementia.
- Each session included a combination of information giving, discussion, looking at the results of the sleep actigraph from the week before, practical exercises including increasing light at particular times and increasing activity.
- There was relaxation exercise and people were given relaxation CD or MP3 files.
- Each session was around an hour.
- The staff member delivering the intervention were supervised by a clinical psychologist and their GP and memory service team will know that they are in the study.

The sessions of the DREAM intervention include:

- ★ Learning about sleep and dementia
- ★ The importance of routine pre-bed and at mealtimes
- ★ Relaxation and bedroom comfort
- ★ Using natural light, morning wake-up light
- ★ Pleasant activities
- ★ Management of daytime naps
- ★ Relaxation, especially at night
- ★ What works? Using skills and strategies in the future

*Give them a few minutes to look through and make any general comments. These prompts are only if not already covered.*

**Q. What are your initial thoughts on the manual we used?**

**Q. What do you think about the design of the manual?**

**Prompts:**

- How do you find the layout?
- Is it easy to read and follow, e.g. not too much text on each page / fonts / colours?
- How do you find the quotes? Prompts relevance, length
- What do you think of the pictures and images – more, less, different?
- How do you find the balance of information giving and discussion?

**Q. What do you think about the content of the sessions?**

**Prompts:**

- Do the topics and examples fit with what your experience is or has been?
- Is there anything important that you feel is missing?
- Is it pitched at the right level for a range of people?
- Is it easy to understand?
- Do the key points stand out?

**Q. What do you think about the structure of the sessions?**

**Prompts:**

- Does the order of sessions make sense?
- What do you think about the length of each session?
- Is there anything else we could do to make it easier to understand?
- What do you think about having relaxation and homework in each session?
- Do you think it is better to give out the manual session by session all at once?

**Brief presentation of findings to date**

- What are your first thoughts on the findings?
- Did anything surprise you that you heard?
- What do you think we could do to address some of the barriers raised? (*Put up slide about what made it harder?*)
- Do you have any suggestions about how to make it easier for people to make use of DREAMS:START? (*Put up slide about what made it easier?*)
- Based on what you have heard today, do you have any other suggestions about changes we could make to the design / content / structure and process the sessions?

**Q. Before we finish, is there anything else you would like to mention that we have not already covered?**

**Thank you for taking part today.**