



The University of Manchester



www.invest-trial.com

Care partners of people with Parkinson's-related dementia

Sabina Vatter

PhD student & Research Assistant (INVEST study)

Contact: sabina.vatter@manchester.ac.uk

Role and profile of care partners

In the UK:

- 7 million (58% women)
- 670,000 care for people with dementia
- Economically save £60bn/year
- Physical and mental health issues

Carers Trust/Carers UK

Care partner



Impact:

- Decreased socialising
- Shift in the relationship
- Negative feelings, stress and burden
- Lower quality of life

→ **'Hidden patients'**

Interviews with spouses

1. ALTERED RELATIONSHIP

"I've just got this person that needs looking after, I haven't got erm, a husband as such or a partner or a friend even, you know. [...] It's like having somebody else's elderly uncle to stay."
- P06, Spouse of DLB

2. CARE PARTNER CHALLENGES

"Sometimes in the morning I get in a panic 'cause I think I can't do this. [...] I have no, no life and I have no future, I can't do anything."

- 12 female spouses
- Mean age: 69 years
- Marriage duration: 46 years

- P07, Spouse of PDD

3. ACCEPTANCE & ADJUSTMENT

"When we got married you got married forever. [...] You say in sickness and in health, well we've had the health bit and now we're on the sickness bit, you know. It's just inevitable and you just have to accept it. [...] And I've got to look after him because it's what I signed up to do all those years ago, you know [laughs]."

- P02, Spouse of PDD

Care partners in INVEST study



- **Acceptable**

- Home
- Flexi
- Choic

“I did feel a bit of pressure because I thought we’ve signed up to do this and I’m not, you know, I’ve not done it enough.”

- Companion 4

- **A shared exper**

- Reminiscing
- Having meaningful conversations
- Learning about each other

... didn’t have this [therapy], we ... wouldn’t have ... e conversations, ... n’t have known ... of this, really.”

Companion 5

... in symptoms

... to meet recommended

... ber of sessions

- **Companion aspects**

- Burden and pressure
- Challenging and effortful

In conclusion

- Some signals of **efficacy**
(↑ communication, reminiscence)
- CST-PD is well **accepted** but needs modifications

Our aim → develop a frictionless therapy:

- Meets the needs of both
- Mutually beneficial
- Minimises companion burden
- Increases companions' skills, knowledge and confidence through training and support



Thank you



- People with PD and their companions
- NHS sites in Greater Manchester, Derby, NW Coast, London (UK)
- Clinical Research Network
- Public and Patient Involvement Representatives
- Trial Steering Committee
- Parkinson's UK
- DLB Society
- Join Dementia Research
- NIHR RfPB funding stream

This presentation presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0613-31058). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.