

Evaluating Support for Carers of People with Dementia

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Background to our project

Background

- ◆ Policy emphasis on dementia
- ◆ National Institute for Health Research call for new research on the organisation of dementia services

Our research

- ◆ In partnership with Dementia UK we designed a project looking at the support for carers of people with dementia
- ◆ Focus on specialist nursing (Admiral Nursing as exemplar)
- ◆ Also interested in the support available in areas without Admiral Nursing

Summary of research

1. Analysis of Admiral Nursing's own administrative data set – almost 25,000 cases since 2005
2. Qualitative research to identify the outcomes of support for carers
3. National survey of carers with an Admiral Nurse and carers in matching areas without Admiral Nursing services – feasibility of using the survey to explore costs and effectiveness
4. Qualitative research in areas with and without Admiral Nursing to understand wider impact of support for carers

The outcomes of support for carers

The focus was outcomes for carers (to inform survey design)

How are carers affected by:

- ◆ good support
- ◆ poor support/ absence of support



We asked about types of support (emotional, financial etc.)
Carers told us about the outcomes of receiving:

- ◆ Specialist carer services
- ◆ Specialist dementia services (impact on carers)
- ◆ And more generic services (social care/GP, etc.)

Interviews and focus groups

35 carers of people with dementia were interviewed or participated in a focus group



Two Areas with Admiral Nursing	Two Areas without Admiral Nursing
6 carers from AN site 1	10 carers from non-AN site 1
12 carers from AN site 2	7 carers from non-AN site 2
18 carers in total from AN sites	17 carers in total from non-AN sites

Findings

The outcomes of supporting carers:

- ◆ Confidence in caring (care self-efficacy)
- ◆ Quality of life
- ◆ Health (mental and physical)

Confidence in caring

Interviewer

What ultimately ... is the result or outcome of you having this Admiral Nurse?

Um, I think confidence is a lot of it, confidence that I can get help, confidence that I'm not alone, there's someone out there to help, who fully understands and who is trained in the specific illness.

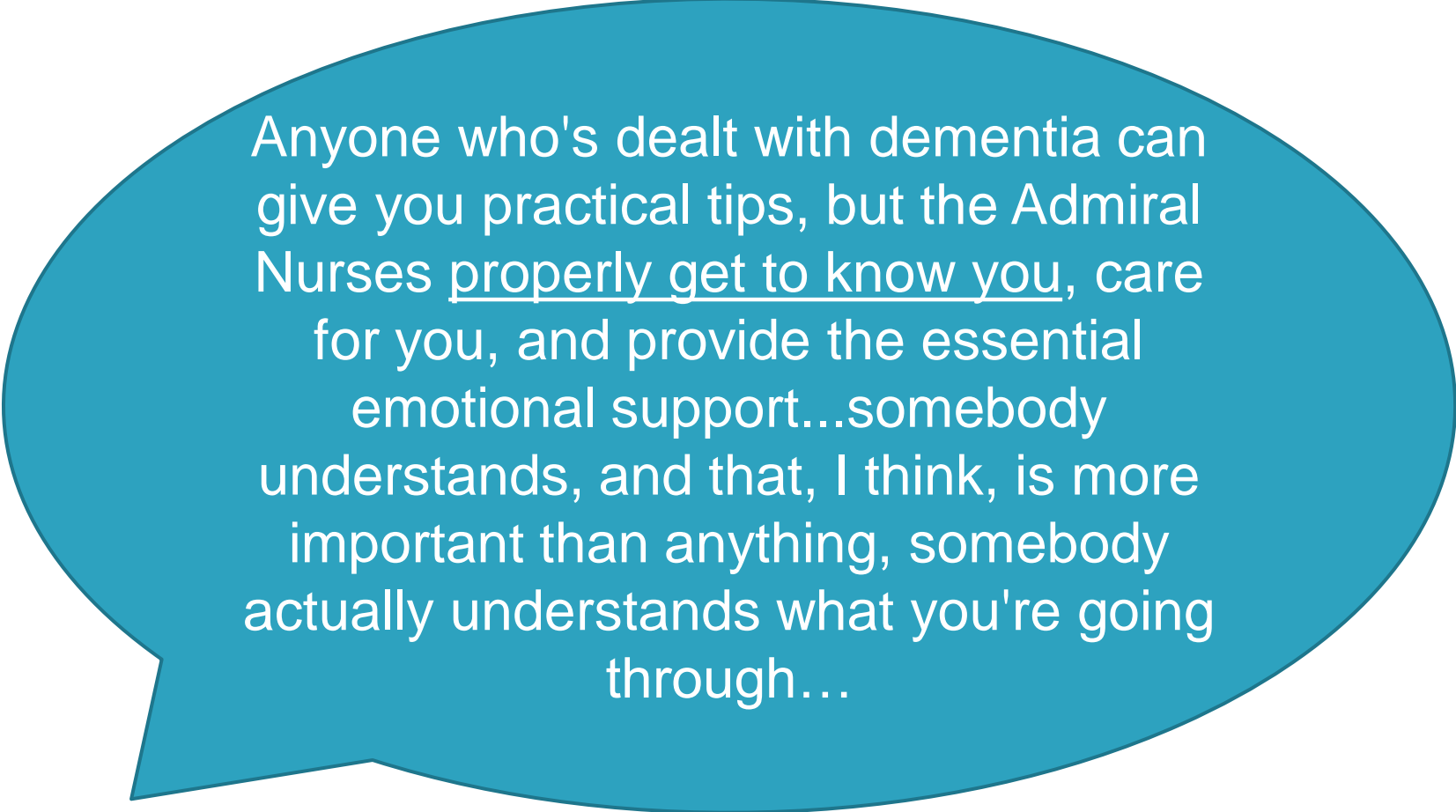
Carer with Admiral Nurse [AN2C7]

Confidence in caring

Key contributors to carer confidence included:

- ◆ Support coming from a specialist in dementia
- ◆ Who worked in a way that enabled them to get to know the carer/person with dementia and their unique situation (requires an investment of time and continuity)

Confidence in caring



Anyone who's dealt with dementia can give you practical tips, but the Admiral Nurses properly get to know you, care for you, and provide the essential emotional support...somebody understands, and that, I think, is more important than anything, somebody actually understands what you're going through...

From Focus Group 1 in Admiral Nursing Area 2

Confidence to handle problems

I just think I feel lost, because we've got a situation and I think I don't know how to handle this... At times I just feel I just don't know where to turn and what to do...

Carer without
an Admiral
Nurse
[NAN2C6]

... it'd be nice for [there to be] somebody that, once you are diagnosed, they know you, [and] the person with it, and come and see you ... and as the illness progresses and deteriorates, you have this support that “Have you tried this?” or “Have you tried that?”

Confidence that you can carry on caring

November and December were horrendous ...I don't think I could have done another 6 months of that without any help and support... Now, I do feel he's getting worse, but I do feel I can cope, and I now have a vision for the future that I know how it will go

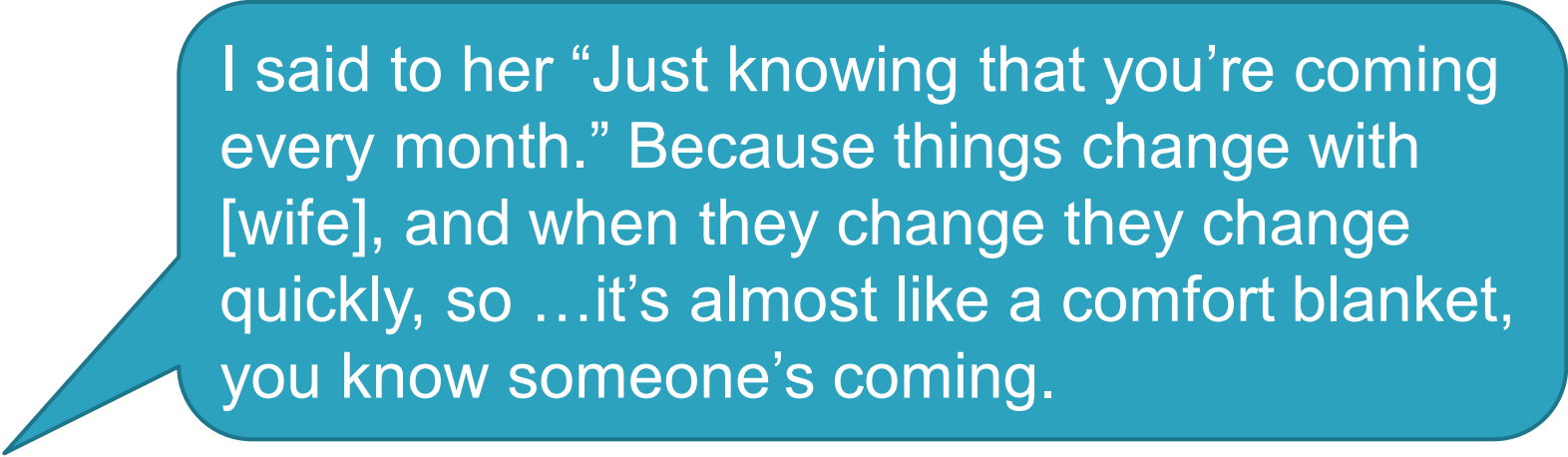
From Focus Group 2 in
Admiral Nursing Area 2

How to measure carer confidence?

1. **Caregiver Self-Efficacy for Managing Dementia scale**
(Fortinsky et al. 2002)

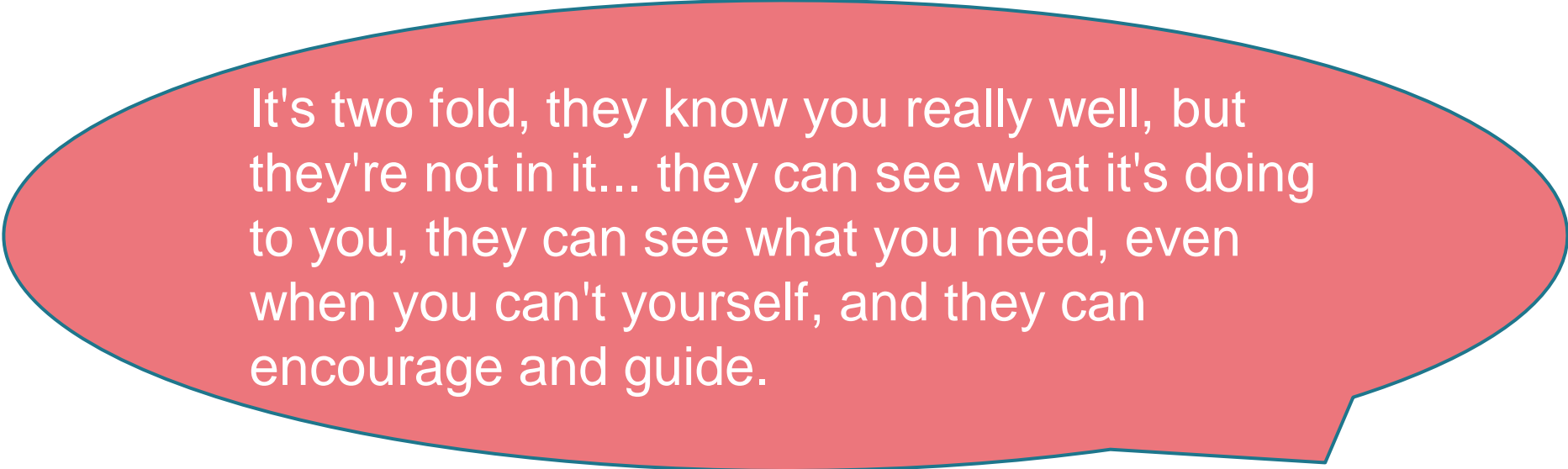


- ◆ But it doesn't cover everything
 - ◆ So we also looked for quality of life questionnaires that measured the other outcomes carers identified
2. **ASCOT Carer** (Rand et al. 2015)
 - ◆ Developed from the Adult Social Care Outcomes Toolkit
 - ◆ Has 'feeling support' in your caring role as an outcome in itself

A blue speech bubble with a tail pointing towards the bottom left.

I said to her “Just knowing that you’re coming every month.” Because things change with [wife], and when they change they change quickly, so ...it’s almost like a comfort blanket, you know someone’s coming.

Carer with Admiral Nurse AN2 Joint

A red speech bubble with a tail pointing towards the bottom right.

It's two fold, they know you really well, but they're not in it... they can see what it's doing to you, they can see what you need, even when you can't yourself, and they can encourage and guide.

From Focus Group 1 in Admiral Nursing Area 2

Survey distribution

- ◆ 16 Admiral Nursing sites selected
 - ◆ Carers contacted through these services by post or email
- ◆ 16 matched areas that do not have Admiral Nursing
 - ◆ Aim was to recruit carers receiving 'usual care'
- ◆ Over 1000 questionnaires distributed February and March 2017

How we found carers for the survey

- ◆ AN carers via AN services
- ◆ Carers in non-AN areas via:
 - ◆ Third sector services in our selected areas
 - ◆ Join Dementia Research
 - ◆ Together in Dementia Everyday (TIDE)
- ◆ **Thanks to everyone who helped!**
- ◆ Aim was to try to get carers who were as like one another as possible
- ◆ Didn't achieve this but can control for differences in analysis
- ◆ 346 completed and usable questionnaires – 46% from AN carers and 54% from non-AN areas

Similarities and differences: characteristics

- ◆ AN carers more likely to:
 - ◆ be caring for a spouse/partner
 - ◆ be the sole or main carer
 - ◆ live in the same household as person with dementia
 - ◆ be caring for someone with a diagnosis of vascular dementia
 - ◆ be aged 75 and over
 - ◆ have no formal educational qualifications
 - ◆ be retired
 - ◆ report 'some' or 'severe' financial difficulties

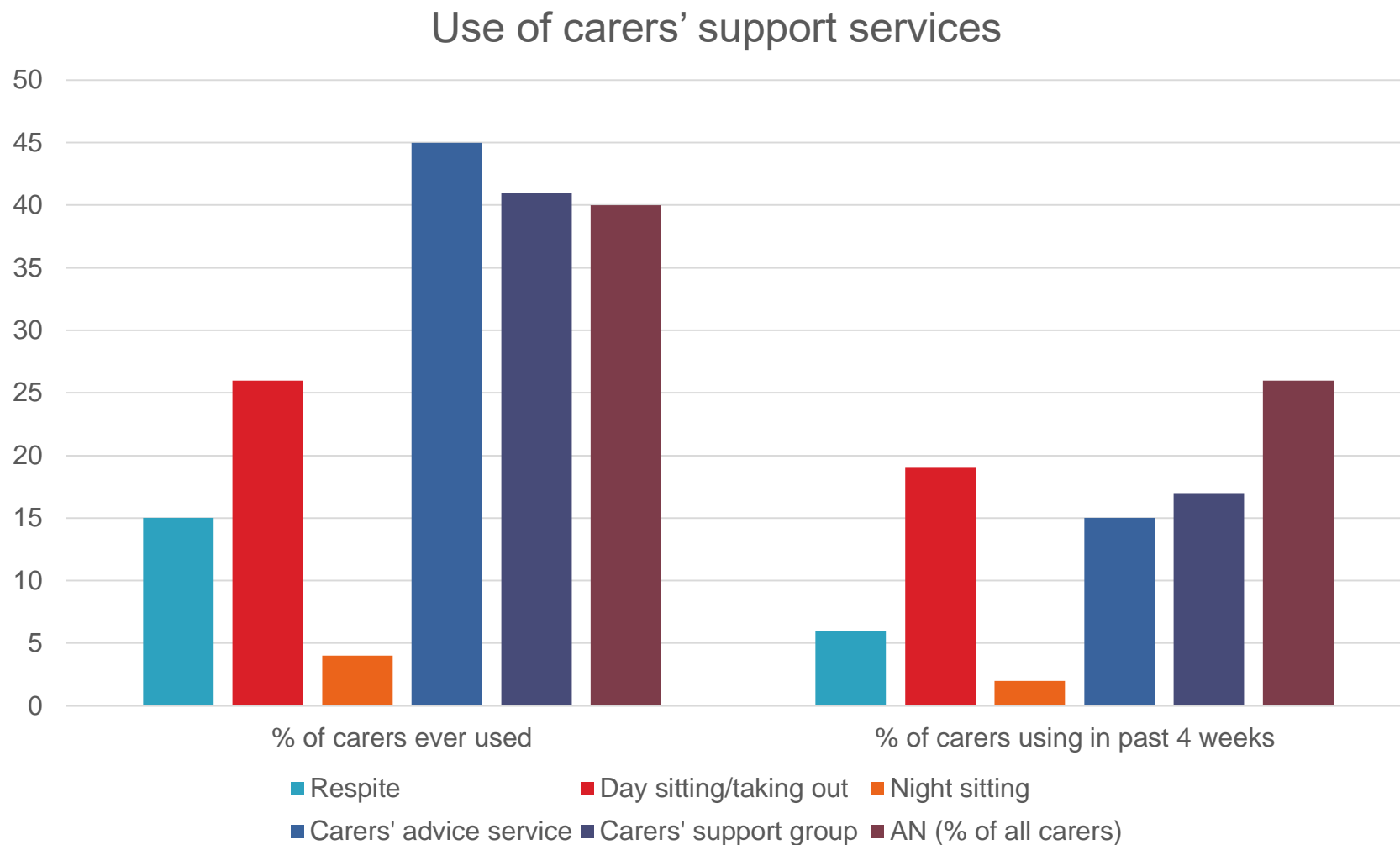
Similarities and differences: caring activity

- ◆ AN carers more likely to:
 - ◆ Provide 'heavy end' caring - personal and physical care
 - ◆ Care for 18 or more hours a day

Similarities

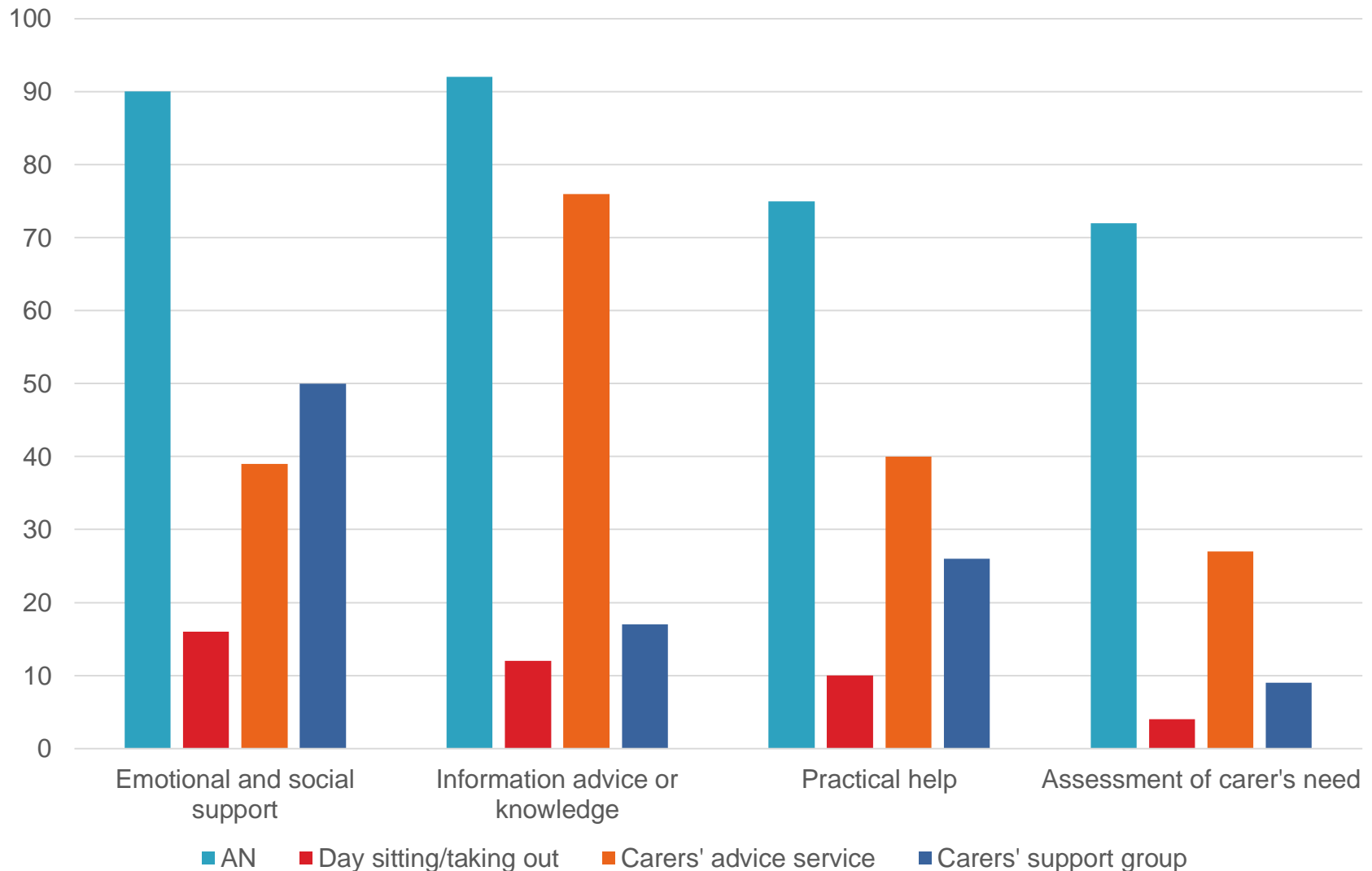
- ◆ Two groups were similar in relation to:
 - ◆ Sex of carer
 - ◆ Sex of person with dementia
 - ◆ Age of person with dementia
 - ◆ Length of time person with dementia had symptoms
 - ◆ Presence of formal diagnosis
 - ◆ Reported severity of dementia
 - ◆ How long caring for person with dementia
 - ◆ Ethnicity of both carer and person with dementia

Service use: carers' support services



Type of support from AN and other carers' services

% of those reporting use of service in past 4 weeks

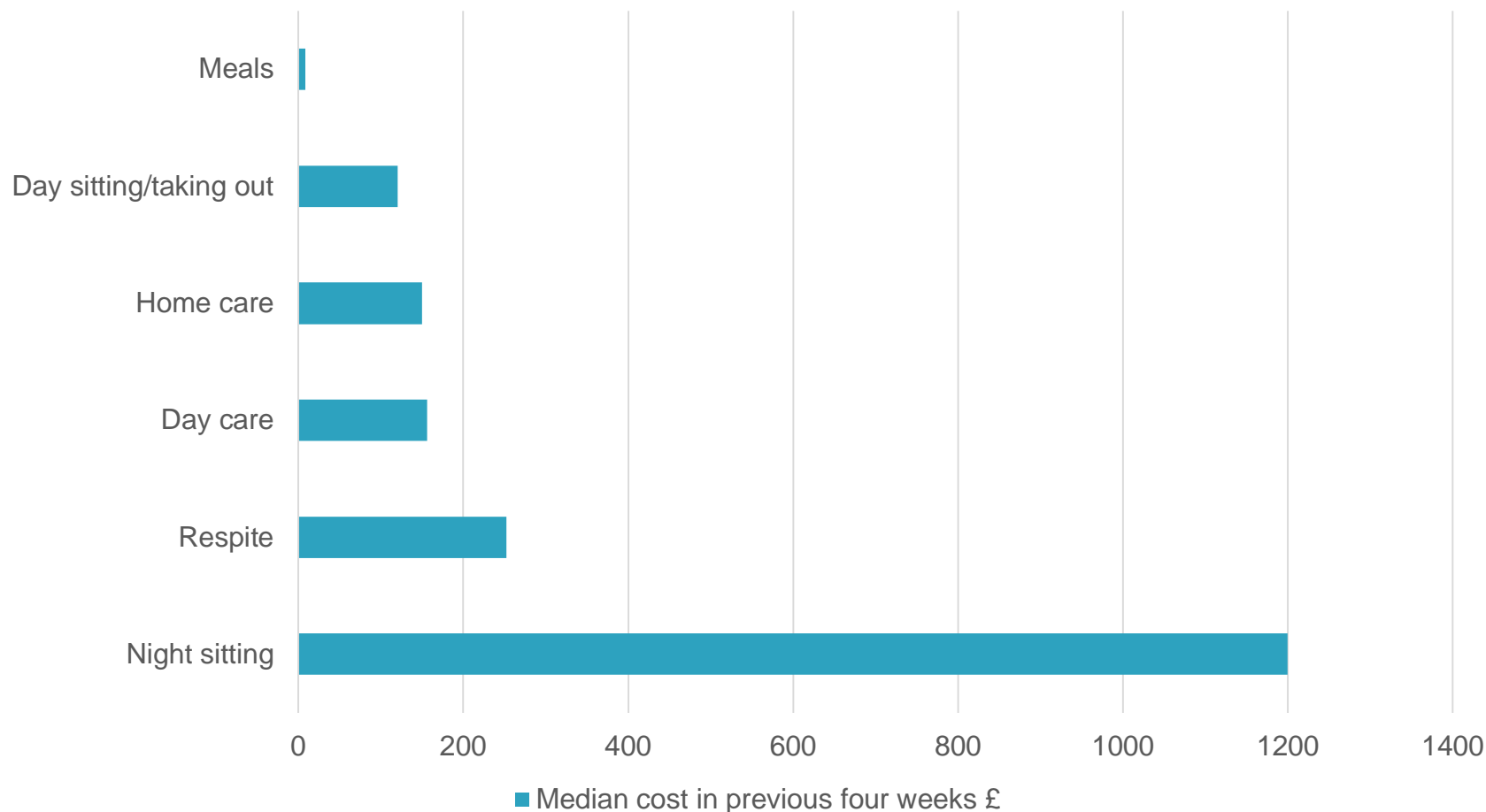


Paying for services

- ◆ Payment was common for both carers' services and for social care services for the person with dementia
- ◆ Examples include:
 - ◆ 46% paid something for memory café attendance
 - ◆ 78% paid for day care
 - ◆ 92% paid for meals
- ◆ Very wide range of costs reported

Average cost of services in past four weeks

Median cost in previous four weeks £



Exploratory Health Economics Analysis: Findings

- Some evidence of better outcomes for carers using AN – but tentative at this stage
- No robust evidence of a relationship between the use of AN services and health care costs
 - But some evidence that AN carers have, on average, lower hospital costs than non-AN carers

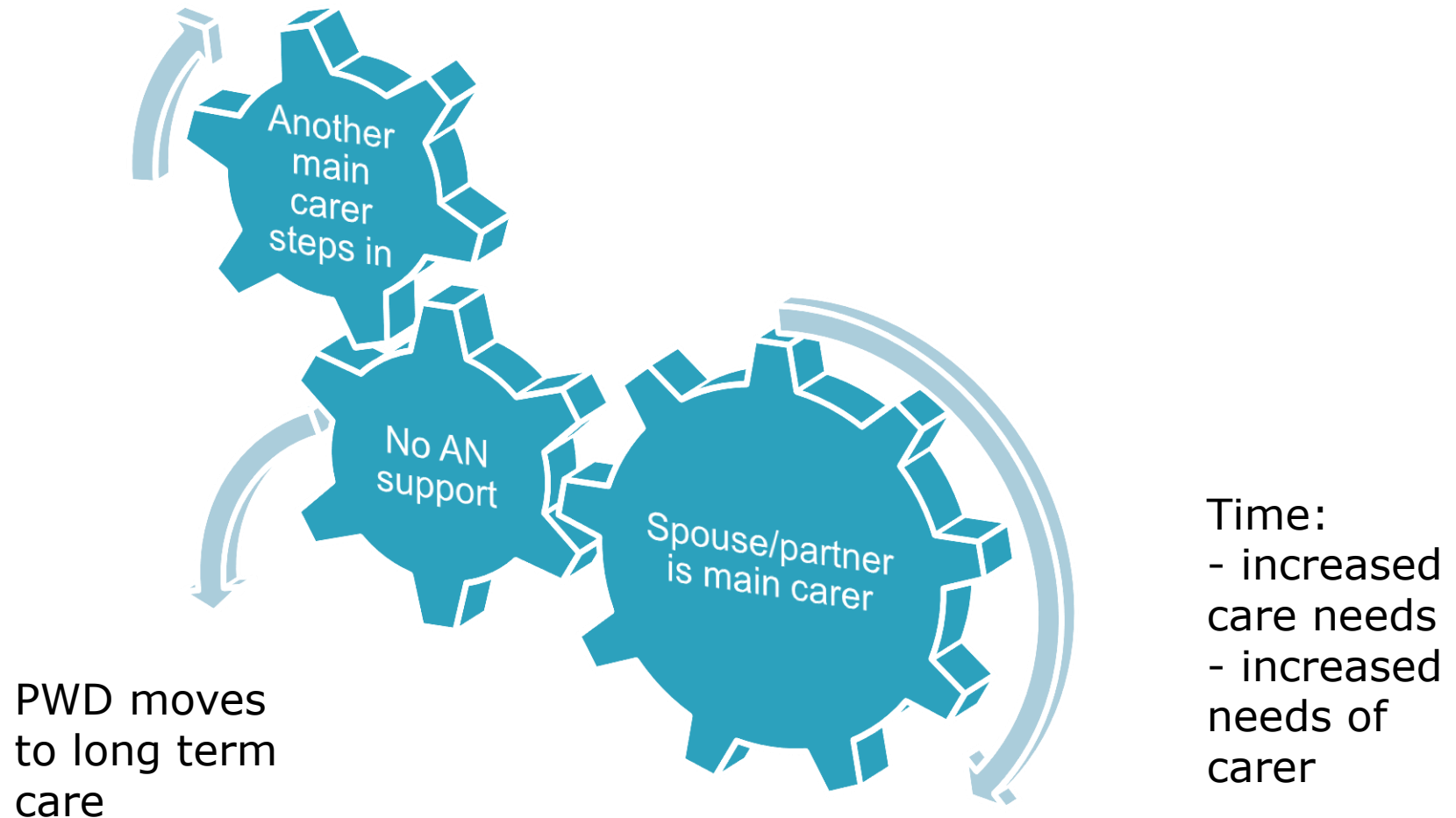
So what does it all mean?

- ◆ Overall, our sample **as a whole** was older and more heavily involved than all carers of people with dementia in the most recent national survey of carers (Survey of Carers in Households 2009/10)
- ◆ Our **AN carers** were older and more heavily involved than the non-AN area carers
- ◆ Feels as if we have found people at different stages of the caring journey
- ◆ And we may be able to start developing some ideas about what AN may be achieving

Is this what AN may be achieving?



Is this what happens without AN?



Take away messages

- ◆ Heavily involved carers – often very old themselves
- ◆ Relatively low levels of practical support in place
- ◆ Those carers who do access support are paying a lot to do so
- ◆ There is no ‘silver bullet’ for supporting carers – different stages of the journey need different sorts of support
- ◆ AN may be playing crucial role with the oldest and most heavily involved ‘late stage’ carers
- ◆ This was a cross-sectional survey, not an intervention study!

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