

WHAT CARERS WANT: SUPPORT FOR THEMSELVES AND HOW THEY EVALUATE CARE BY OTHERS

Jo Moriarty

BACKGROUND

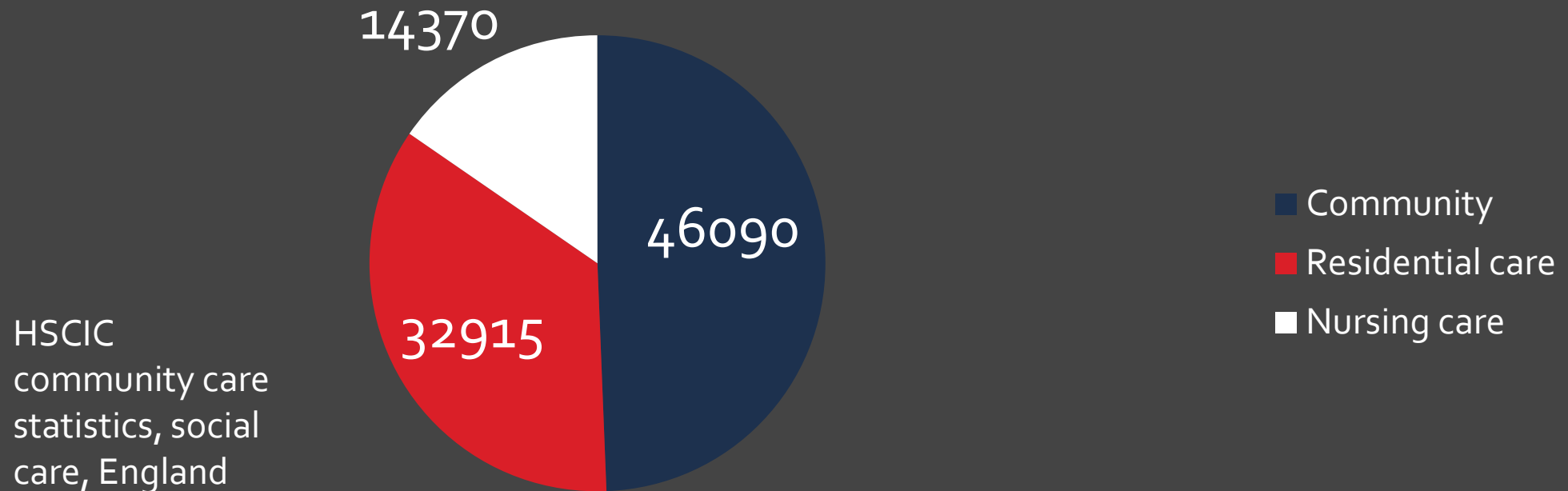
Most care for people with dementia is provided by families

WHY IT'S IMPORTANT

- Numbers of people affected
- Complexity of support needs
- Effects on carers

OVER 80K PEOPLE WITH DEMENTIA RECEIVING SOCIAL CARE SERVICES

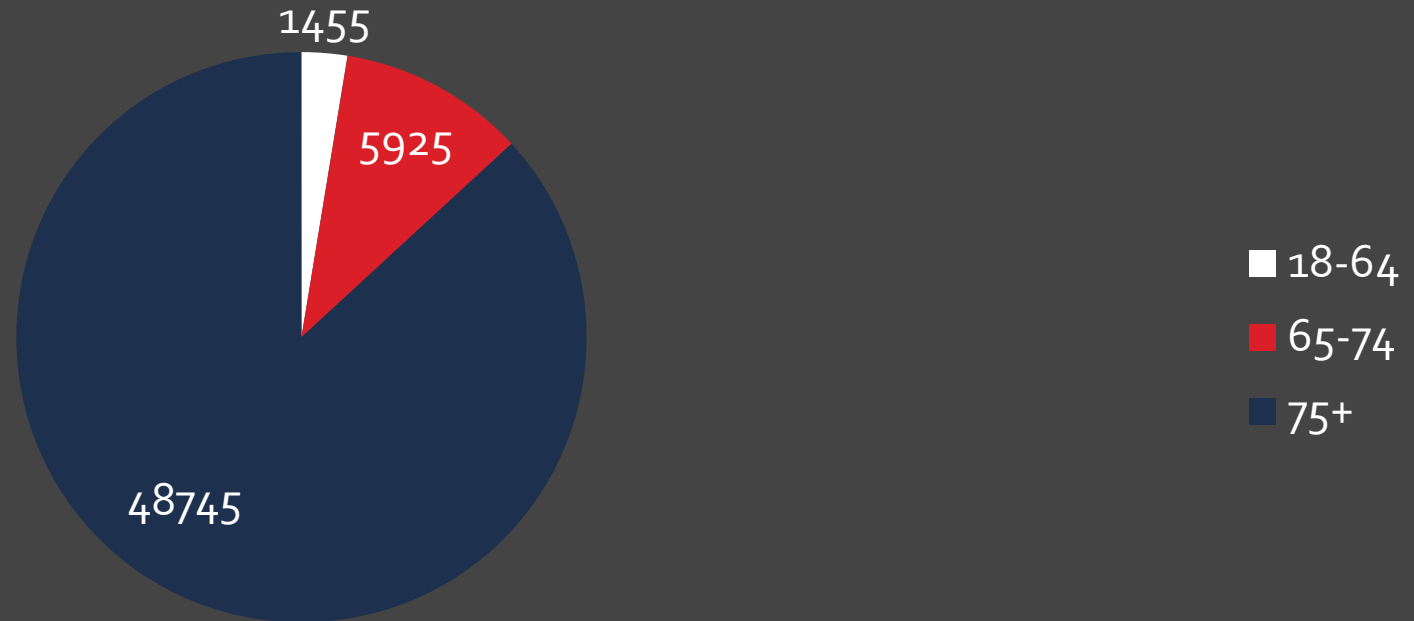
People with dementia receiving CASSR commissioned services in 2013-2014



OVER 50K REVIEWS

Reviews of people with dementia completed in 2013-2014 (existing clients)

HSCIC community
care statistics, social
care, England



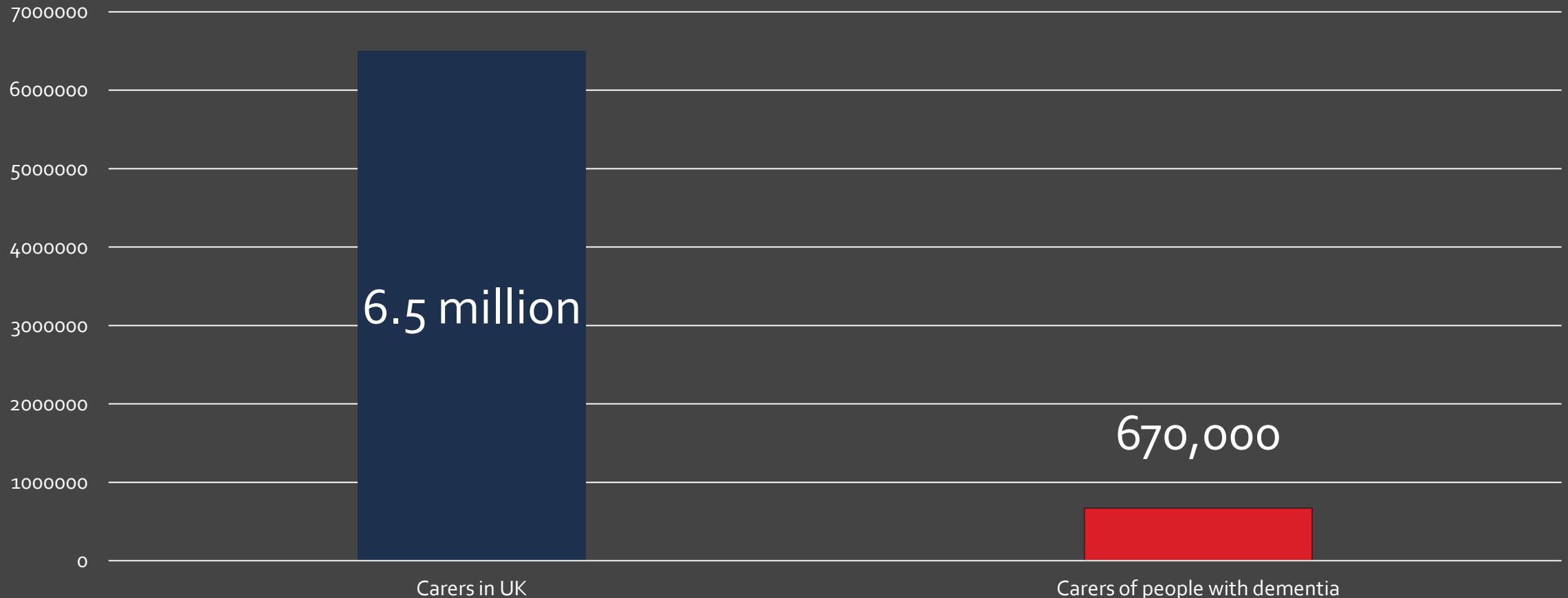
BUT A GREAT BIG BUT.....

- About 1.25 million people receive services from their local council
 - Likely that many people recorded as 'frail' have dementia
 - Data on people receiving self directed support not subdivided by dementia
 - Excludes people who are assessed but refuse services
 - Excludes people not meeting eligibility criteria
 - Few reliable studies on proportion of people with dementia receiving social care services (& they are from 1980s/90s)

SO...

- Data on use of social care services likely to be under estimate
- But we know that a major part of adult social work role is supporting people with dementia and their carers

JUST OVER 1 IN 10 CARERS CARE FOR SOMEONE WITH DEMENTIA

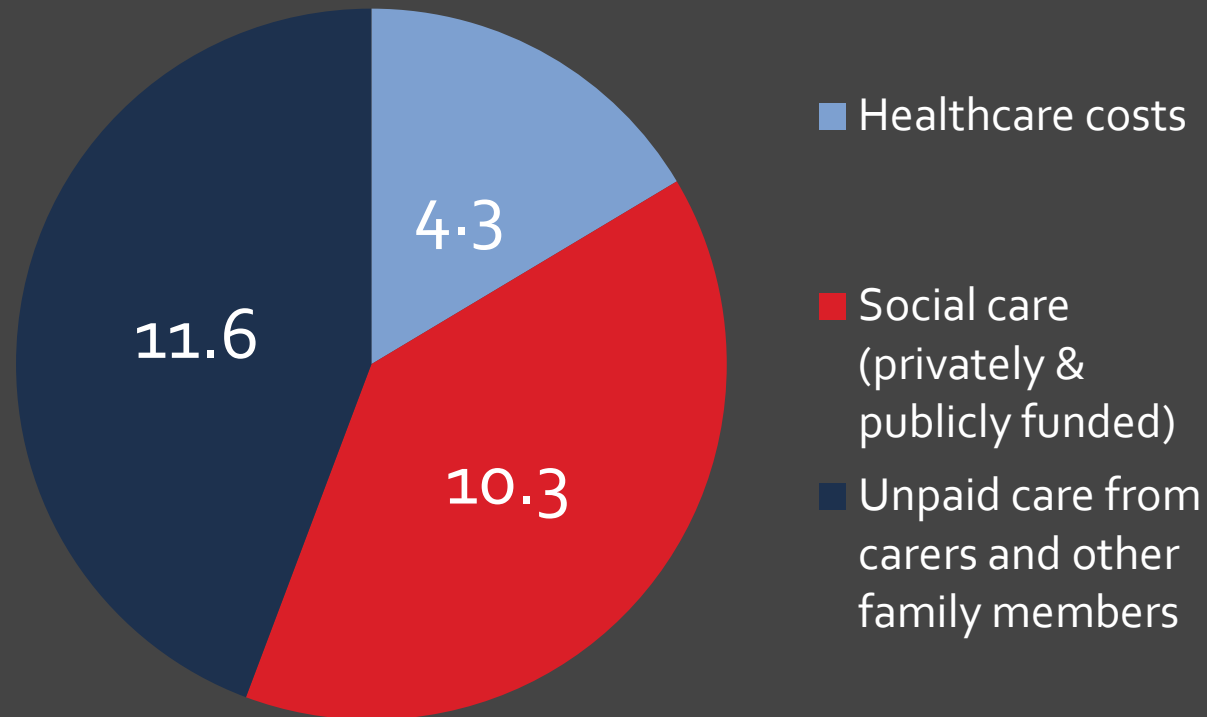


DEMENTIA UK, 2ND EDITION (2014)

'This report, the most comprehensive review of dementia in the UK to date, shows that there will be 850,000 people with dementia living in the UK at the next election, more than ever before. The cost of this is currently £26 billion a year – enough to pay the energy bills of every household in the country. This price tag is set to rise as the number of people with dementia grows. Most strikingly, the report found that carers and families currently shoulder two-thirds of the cost themselves'

DEMENTIA UK REPORT ALSO ESTIMATED

Cost of dementia care each year



Total costs amount to £26.3 billion per annum, or an average of £32,250 per person with late-onset dementia

DIFFERENT TYPES OF SUPPORT

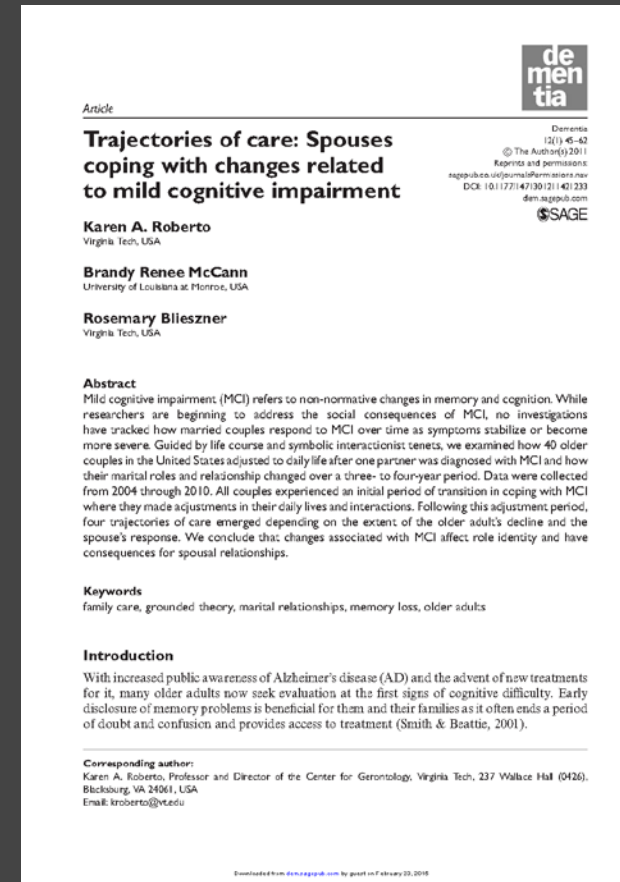
Dementia is a progressive condition so carers' support needs will vary

THINKING ABOUT TRAJECTORIES

- Different illnesses have differing trajectories
 - Dementia typically presents as a 'prolonged dwindling' (Murray et al, 2005)
 - Alzheimer's Society suggest that, on average, people live for 8-10 years after symptoms begin
 - But affected by age at which get dementia (later it is, the shorter the time)
 - Also affected by stage at which dementia is diagnosed (later it is, the shorter the time)

STUDY OF SPOUSES FROM THE US

- Interviewed 40 couples and followed up over 3-4 years
- Carers responded in different ways over time
 - From adjusting to maintaining (more minor)
 - From partner to manager (taking over certain roles)
 - From intertwined to parallel (in long term care)
 - From interdependency to dependence on others



NEW DEMENTIA CHALLENGE



'In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia (p5)'

WHAT ARE THE IMPLICATIONS FOR CARERS?

'I think it's very confusing for carers, especially if somebody's just been diagnosed with dementia. Where does the carer go for support? Where can they get respite? Where can they find advice and information about finances? So I think yeah, there are things that could be improved a lot'

(Donna, Volo6)

Major theme of our NIHR SSCR study was the need not for more information but better quality information

LEAFLETS ARE NOT ENOUGH!



...trying to get [this carer] to understand the terminologies that are being used ... is really difficult on the phone. Hence [I am] going to ... take ... leaflets that have information about the diagnosis that [her husband] has ... I think I need to go and do a home visit and sit down and do a face to face and get her to understand a little bit

(Ifrah, Worker20)

NOT JUST SIGNPOSTING

'We basically provide support and advice and information for people with dementia and their carers, and that can be either through telephone calls, it can be sending out information leaflets, we have lots of fact sheets. It can be people accessing us through our website and we run support groups throughout the area'

(Donna, Vol 06)

Different types of information in different formats

IMPACT ON CARERS' PSYCHOLOGICAL HEALTH

- NUMEROUS studies have shown that between a quarter to a half of carers of people with dementia experience psychological stress
 - Linked to problems behavioural problems as person with dementia finds it harder to communicate (feelings of frustration)
 - Carer's physical health
 - Long term impact of caring over time
 - Effects caring has on social support

START STUDY

- Based on US course for carers
- Eight sessions
 - Dementia
 - Carer stress
 - Where to get emotional support
 - Managing behaviour
 - Relaxation
 - Carers practised at home (Livingston et al, 2013, Knapp et al, 2013)

IMPLICATIONS FOR SOCIAL CARE

- Highlights importance of carer's assessments
- Not an 'add on' or tick box process
- Research shows many carers are unaware of rights to an assessment or even if they have been assessed

WHAT SIMILAR APPROACHES WOULD WORK?

That's things like, for instance the way it runs [here] is that we have a six week course, twice a year, free. We have different speakers come each week to talk about things from basic dementia awareness, to benefits, to Power of Attorney

(Brooke, Vol 16)

Consider and review existing courses for carers

GETTING A BREAK

What people need is some time off. And they've said that repeatedly and loudly. They want to get away from it for just a couple of hours, four hours, a week. Just to get their head out of the situation. Somebody described it to me as being in that zone. You need to get out of that zone (Worker 18)

Making sure carers get a break from caring

TWO DAUGHTERS: KATHRYN



“A couple of years... well, four or five years ago really, it became apparent that she had deteriorated, she wasn't changing her clothes, washing, she really didn't know what was happening. She couldn't even really make herself a cup of tea. My sister organised meals on wheels for her, and she'd go in on a Saturday morning and find half of the meal in the fridge”

CARER07

... AND KLARA



“Just over about two years ago, I noticed her short term memory was getting very poor. And that’s when things started to go slightly more downhill. Her long term memory is still as good as ever. In fact it’s better than most. She can remember her schooldays and her young married life and bringing up all the children. Things that actually happen today, this week, or last week, is very poor”

CARER20

SUPPORT THEY RECEIVE

Kathryn

- Mother goes to day centre twice a week
- Has break planned with granddaughters while mother will go for short stay in care home
- Incontinence pads provided by council
- Attends a carers group
- Joined a walking group
- Some limited support from sister

Klara

- Mother attends weekly social club
- They attend monthly Age UK reminiscence group together
- Mother had successful short stay in care home
- Attends carers group and now runs carers café
- Went on a self esteem course
- Some limited support from siblings

RECOGNISING IMPACT ON RELATIONSHIPS

My mother's condition means she is living more in the past than the present most days and is unable to remember what I tell her or what is planned for the day. This makes some days very lonely and also frustrating as I repeat for the tenth time what I have planned for dinner. But she is also sometimes a complete joy

Loneliness or
reduced social
networks

RECOGNISING REALITY OF LOSS

They make a point of knowing when the carer's birthday is, so you get a birthday card from your mum ... and Christmas ... they take a photograph of them during the year, when they're doing some activity. So they make a Christmas card and put her photograph in it, and get her to sign it, which she can just about do

Sometimes little things make a difference

KATHRYN & KLARA ON SOCIAL SUPPORT

I never had a big social life ... one of my neighbours has become a good friend and she brings over a bottle every now and again and we shut ourselves in the dining room and have a good old natter

Kathryn

Being a trained counsellor, [Keira's] s been able to give me a lot of sort of support and just someone to talk to who is just there for me and I know that I can call ... She's always got time to talk, which is lovely. She's been a real rock

Klara

THEIR SHARED CONCERNS

- About their own health
- About the future
 - For themselves as women on limited incomes
 - For their mothers in terms of arranging long term care
 - About prospect of cutbacks to services
- How to capture the difference between mechanistic and personalised care?

JOINT INTERVENTIONS

- Emphasis on joint interventions such as dementia cafés
- Effectiveness of joint reminiscence groups for carers and people with dementia evaluated by Woods et al (2012)
- Carers became more stressed
- Wondered if joint interventions always help



Dementia café Market Harborough

CONTINENCE

- Very little evidence on what helps for carers and what sort of advice they are given (Drennan et al, 2013)



Somerset Partnership NHS Foundation Trust

ASSISTIVE TECHNOLOGY

- Review suggested that we need more information on cost effectiveness (Bowes et al, 2013)
- Some promising options (medication reminders) but studies not just for dementia
- US systematic review also commented on research quality (Godwin et al, 2013)



Image from *At Dementia*

QUALITY OF SERVICES

- HISCIC survey of carers using social care services found high levels of satisfaction
- But concerns about negative impact of a particular service on quality of care for person with dementia major reason for refusing services

UNDER REPRESENTED CARERS AND EQUALITIES

- Increase in numbers of carers from black and minority ethnic groups
- Neglect of LGBT carers
- Young carers – caring for grandparents or older parents?
- Young onset dementia

DISCUSSION

Some suggestions for discussion and thanks

DISCUSSION

- What are the main gaps in support for carers?
- What happens when carers refuse support?
- What are the risks of carers being differentially affected by cutbacks?
- Will the Care Act 2014 make a difference?

DISCLAIMER

- This presentation includes independent research funded by the NIHR School for Social Care Research. The views expressed in this presentation are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health/NIHR

Thank you for
listening

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SOURCES (1)

Slide number	Source
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7	Carers UK briefing on carers http://www.carersuk.org/professionals/policy/policy-library/facts-about-carers-2014 Alzheimer's Society data on carers of people with dementia http://www.alzheimers.org.uk/statistics
9, 10	Dementia UK update report http://www.alzheimers.org.uk/dementiauk

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