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Carers: using economic evidence to make the case for better support

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People with dementia & their carers

In the UK today there are **816,000 people with dementia**:

- Two-thirds are women
- Two-thirds of people with dementia live in the community; one third live in a care home.

And there are **670,000 unpaid carers** supporting them

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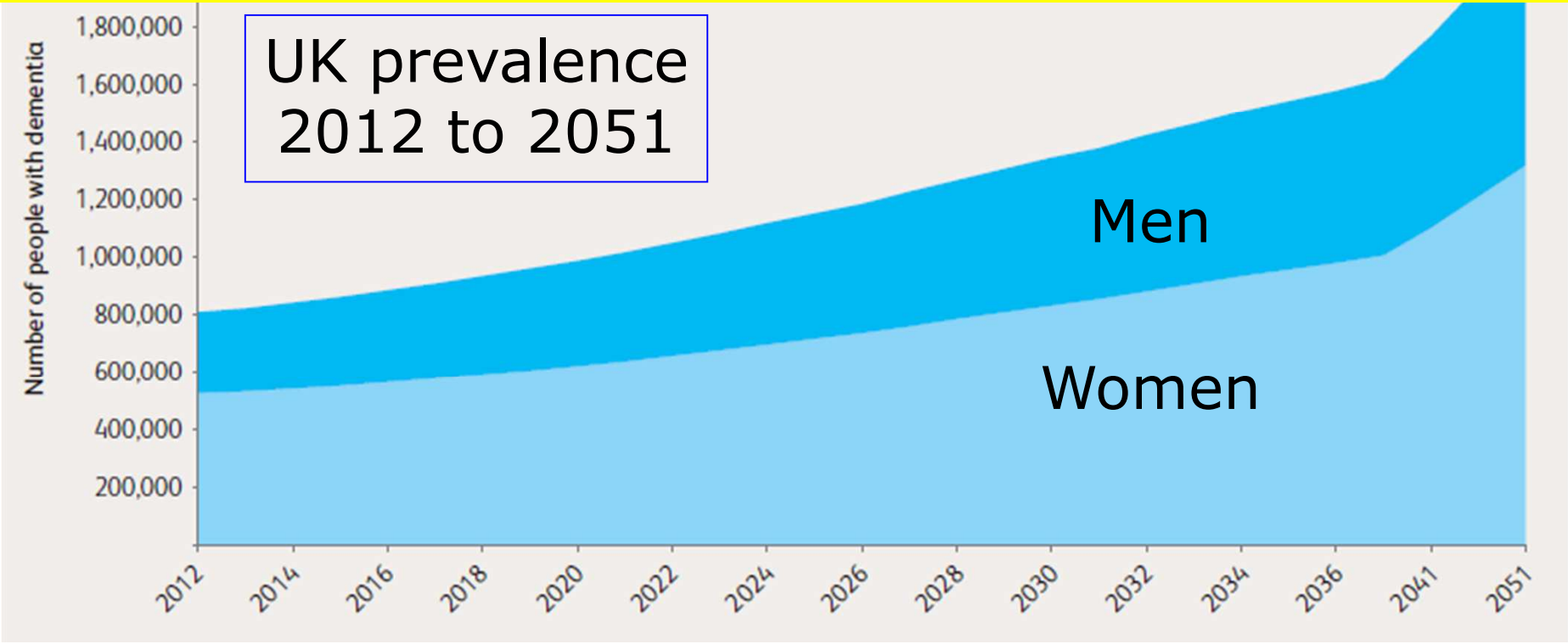
And those numbers will continue to grow

There is evidence that prevalence rate might be slowing, but total number will increase.



Prince et al *Dementia UK; 2nd Edition* 2014; Matthews et al, *Lancet* 2013

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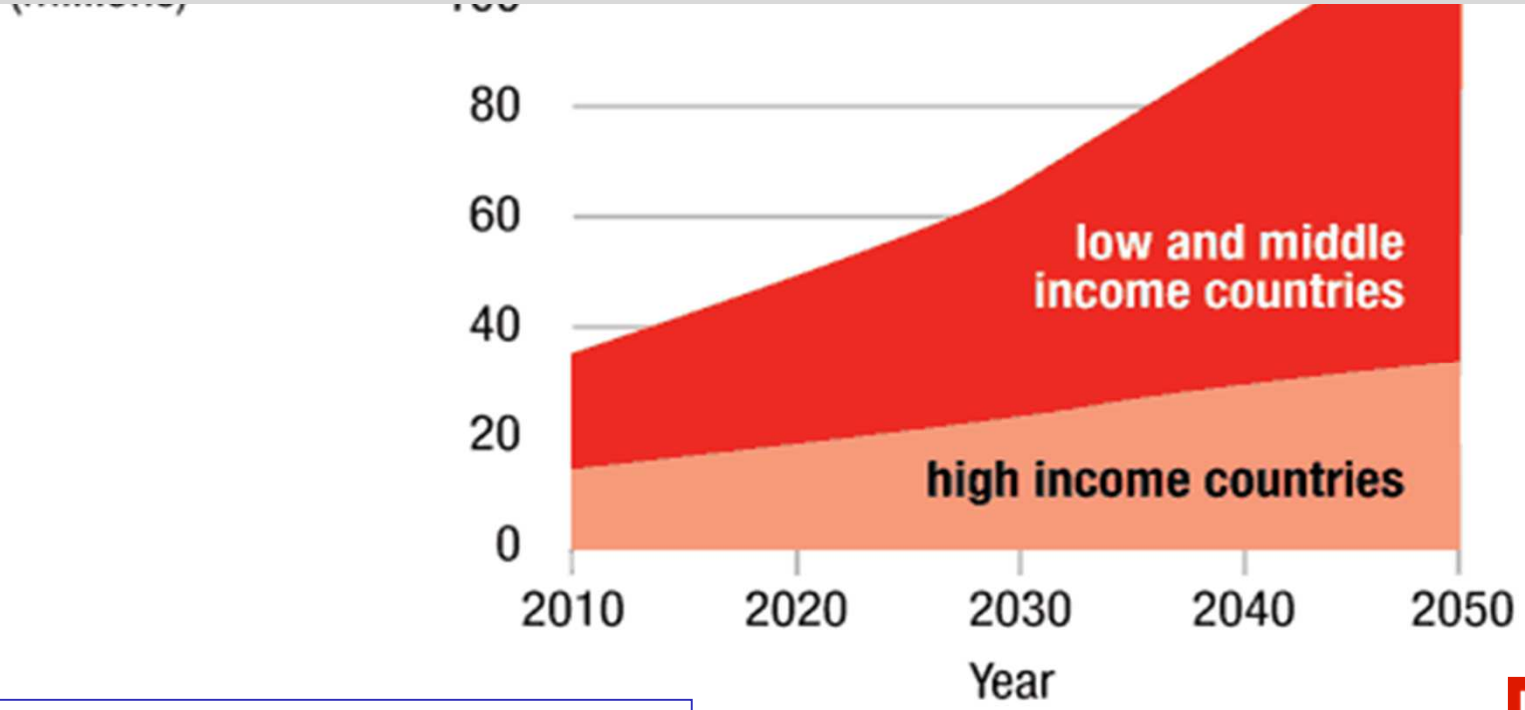
But higher growth in low-income countries

These big increases in total prevalence means:

- **… big increases in reliance on unpaid carers**
- **… and/or big increases in health & social care service costs**



Alzheimer's Disease International

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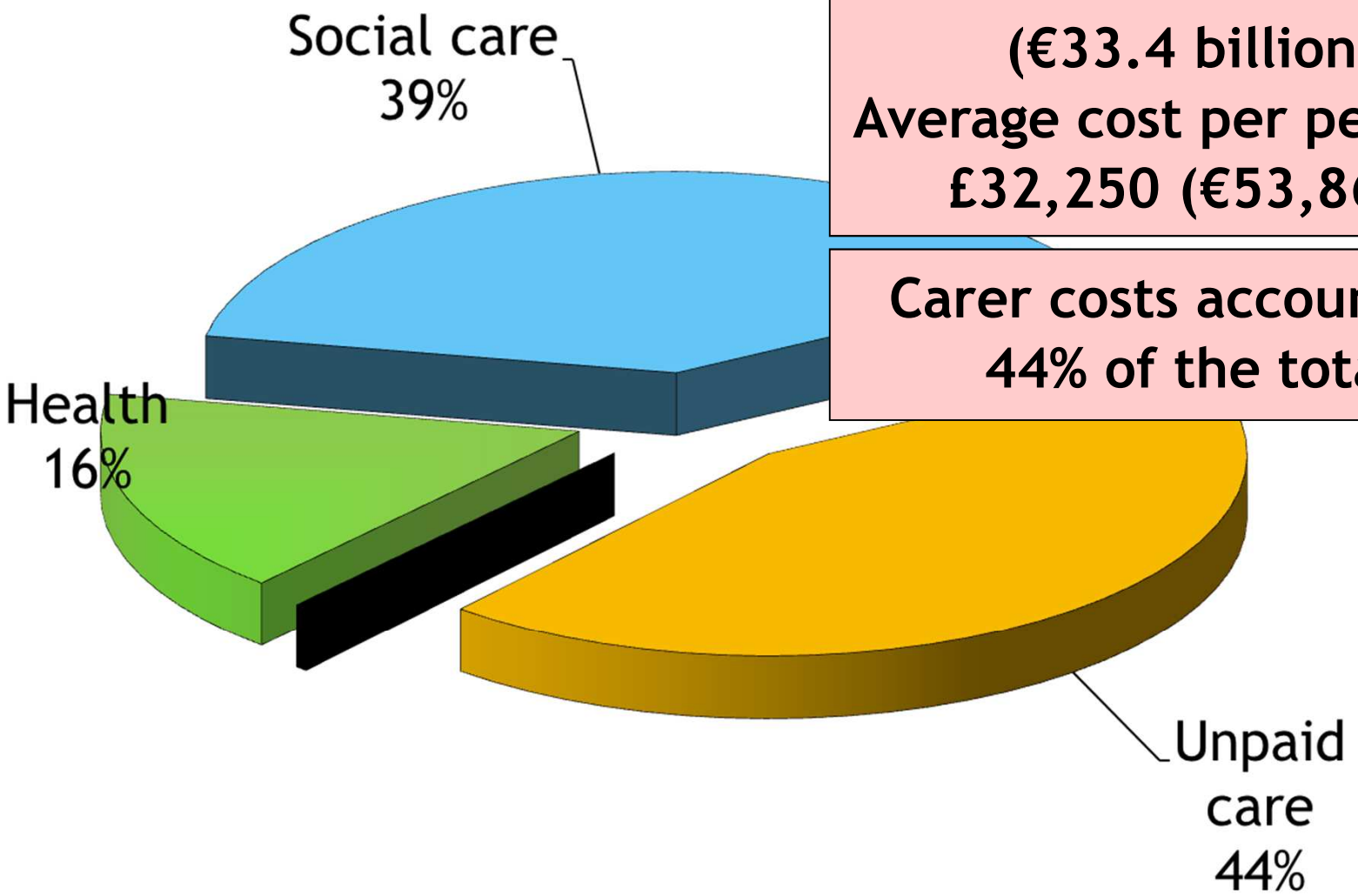
Carer contributions & need for support

- ‘Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers’ (*Prime Minister’s Challenge on Dementia*, 2012)
- Unpaid carers – the unsung heroes of dementia care
- High out-of-pocket and ‘hidden’ costs → → →

Annual cost of dementia in the UK

Total cost = £26.3 billion (€33.4 billion)
Average cost per person = £32,250 (€53,860)

Carer costs account for 44% of the total



Estimates by PSSRU for *Dementia UK: 2nd edition* (Prince et al, 2014)

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Carer contributions & need for support

- 'Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers' (*Prime Minister's Challenge on Dementia*, 2012)
- Unpaid carers – the unsung heroes of dementia care
- High out-of-pocket and 'hidden' costs …
- … and these carer costs will grow as prevalence increases, and also as health and social care budgets get stretched.
- Many carers experience a lot of stress
- So, what can be done to support them?

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Supporting carers: making the case

Why should governments 'care about carers'?

Because:

- … They are the **'frontline'** of social and health care
- … Carers '**are people too**' and we should look after their wellbeing
- … Healthy, happy carers can improve healthy and wellbeing for **people with dementia**
- … Potentially it will either **save money**
- … or it will ensure **better value for money** in use of health & social care resources.

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Decision-makers need economic evidence

Why?

- Because resources are **scarce.**
- So we cannot meet every health / care need or respond to every request or preference.
- And so we must **choose** how to get the best out of our available resources.

Consequently …

- … any new treatment or care arrangement will be looked at very carefully: Is it **effective**? And is it **cost-effective**?

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START: a manual-based coping strategy

Individual programme (8 sessions, 8-14 weeks, delivered by psychology graduates + manual); carers given techniques to:

- understand behaviours of person they care for
- manage behaviour
- change unhelpful thoughts
- promote acceptance
- improve communication
- plan for the future
- relax
- engage in meaningful, enjoyable activities.

Family carers of people with dementia

Built on experience in USA with the *Coping with Caregiving* programme

Livingston et al *BMJ* 2013; Coon et al *Gerontologist* 2003

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STrAtegies for RelaTives programme: structure

Introduction: Learning about dementia, stress in carers, and understanding behaviours of the recipient of care (especially those that carers found difficult). Behavioural management techniques, skills to take better care of themselves (including changing unhelpful thoughts), relaxation, increasing and assertive communication, promoting acceptance, sources of emotional support, and positive reframing.

Future needs of the family member with dementia: Information about care and legal planning, specifically adapted to the United Kingdom. We gave the carers information leaflets about making common decisions as appropriate at an individual level

Planning pleasant activities: This used the idea that it is possible, beneficial, and pleasurable to incorporate small pleasant activities into a caring day.

Maintaining skills learnt over time: Carers given homework tasks to complete between sessions, including relaxation, identifying triggers and reactions to challenging behaviours, and identifying and challenging negative thoughts. Therapist and carer both had a manual; the carer filled in and kept their own manual. Relaxation exercises used in sessions were recorded on a CD and given to the carers. We defined adherence to therapy on clinical grounds as participating in five or more sessions

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Evaluating START: a randomised trial

Manual-based **coping strategy** programme compared to usual support for family carers (& people with dementia)

Pragmatic, multicentre, **randomised controlled trial**

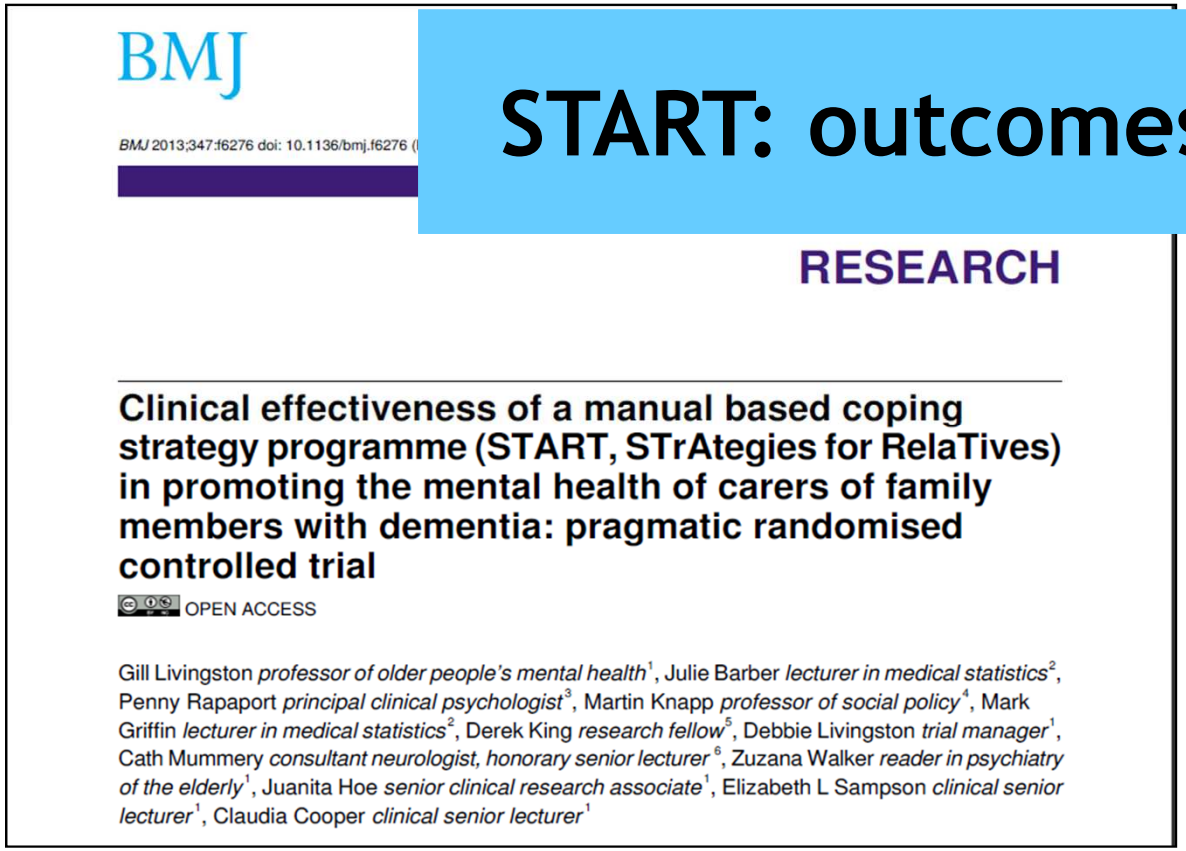
N = 260 family carers of people with dementia recruited from three Mental Health Trusts and a tertiary service in England.

We compared **effectiveness and cost-effectiveness** of START and usual treatment/support – first, over 8 months; and then over 24 months:

- Health & quality of life outcomes for carers
- Health & quality of life outcomes for people with dementia
- Service use and costs for carers & people with dementia

Livingston et al *BMJ* 2013 & *Lancet Psychiatry* 2014; Knapp et al *BMJ* 2013

START: outcomes at 8 months



BMJ

BMJ 2013;347:f6276 doi: 10.1136/bmj.f6276

RESEARCH

Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial

OPEN ACCESS

Gill Livingston *professor of older people's mental health*[1], Julie Barber *lecturer in medical statistics*[2], Penny Rapaport *principal clinical psychologist*[3], Martin Knapp *professor of social policy*[4], Mark Griffin *lecturer in medical statistics*[2], Derek King *research fellow*[5], Debbie Livingston *trial manager*[1], Cath Mummery *consultant neurologist, honorary senior lecturer*[6], Zuzana Walker *reader in psychiatry of the elderly*[1], Juanita Hoe *senior clinical research associate*[1], Elizabeth L Sampson *clinical senior lecturer*[1], Claudia Cooper *clinical senior lecturer*[1]

START improved carer **mental health** and health-related **quality of life** over 8 months.

Carers with *usual support* were 4 times more likely to have **clinically significant depression** than carers with *START*; HADS-total = 2.10 (95% CI 0.51 to 3.75).

Small incremental **QALY gain** for START group; mean 0.042 (95% CI 0.015 to 0.071). *(QALY = quality-adjusted life year)*

Livingston et al *BMJ* 2013

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Cost-effectiveness at 8 months

BMJ

BMJ 2013;347:f6342 doi: 10.1136/bmj.f6342 (Pu

RESEARCH

Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial

OPEN ACCESS

Martin Knapp *professor of social policy; professor of health economics*[1 2], Derek King *research fellow*[1], Renee Romeo *lecturer in health economics*[2], Barbara Schehl *visiting student*[1], Julie Barber *lecturer in medical statistics*[3], Mark Griffin *lecturer*[4], Penny Rapaport *principal clinical psychologist*[5], Debbie Livingston *trial manager*[6], Cath Mummery *consultant neurologist*[6], Zuzana Walker *reader in psychiatry of the elderly*[6], Juanita Hoe *senior clinical research associate*[6], Elizabeth L Sampson *clinical senior lecturer*[6], Claudia Cooper *clinical senior lecturer*[6], Gill Livingston *professor of older people's mental health*[6]

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Cost of **START** was **offset** by reduced use of other services by carers over 8 months. START is **cost-effective**.

Carers getting START had slightly but **not significantly higher costs** (£252; 95% CI -28 to +565), adjusting for baseline.

Cost-effectiveness: £118 (€201) per 1-point change on **HADS-total**; and £6000 (€7620) per additional **QALY** (quality-adjusted life year) … measuring carer service use only.

Knapp et al *BMJ* 2013

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Outcomes & cost-effectiveness at 24 months

Effects on carers:

- Better mental health: carers with usual support were 7 times more likely to have clinically significant depression
- Significantly better quality of life

Effects on people with dementia:

- No differences in health status or quality of life
- Some delay to care home admission (not (yet?) significant)

Service costs go up in both groups over time; but care home costs go up more for people in the usual care group.

Cost-effectiveness: START has better outcomes and doesn't cost any more … It is clearly cost-effective.

Livingston et al *Lancet Psych 2014*

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Other dementia actions that affect carers

- **Risk reduction** ('prevention') will reduce need
- **Screening** – better identification & response
- **Carer support** – new Carers Strategy for England

Carers strategy for England 2014-16

Four priority areas:

1. Identification and recognition: Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset in designing local care provision and in planning individual care packages.

2. Realising and releasing potential: Enabling those with caring responsibilities to fulfil their education and employment potential.

3. A life alongside caring: Personalised support both for carers and those they support, enabling them to have a family and community life.

4. Supporting carers to stay healthy: Supporting carers to remain mentally and physically well.

Dept of Health *Carers Strategy: Second National Action Plan 2014-2016*

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Other dementia actions that affect carers

- Risk reduction ('prevention') will reduce need
- Screening – better identification & response
- Carer support – new Carers Strategy for England
- **Staff skills training** – e.g. cognitive stimulation therapy can improve cognition
- **Medications** – can slow disease progression
- **Home-based care** – reablement has potential
- **Case management** – helps carers coordinate care
- **Attitudes** – growing public awareness reduces stigma and encourages community support

For each of these, decision-makers need economic evidence

- The **overall costs** of a health problem or disability, and how those costs are distributed
- The cost of an **intervention** (e.g. a psychological therapy or drug) **compared to its alternative(s)**
- The cost of an intervention **compared to savings** it generates (and how any savings are distributed)
- The cost of an intervention relative to **outcomes** it achieves (& compared to alternative interventions)
- Understanding of how **economic incentives** might change patterns of behaviour.

More useful but more complicated

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Final comments

- The essential roles played by unpaid carers are **better recognised** today …
- … but many (most?) carers still feel they are **not getting enough help and support**.
- START shows there are ways to **improve carer health and quality of life**, without harming the person receiving care … and it is **cost-effective**.
- More generally, decision-makers need **economics evidence** to help them make better decisions …
- … They need reassurance that resources are used both **effectively** and **cost-effectively**.

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Thank you for your attention

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