



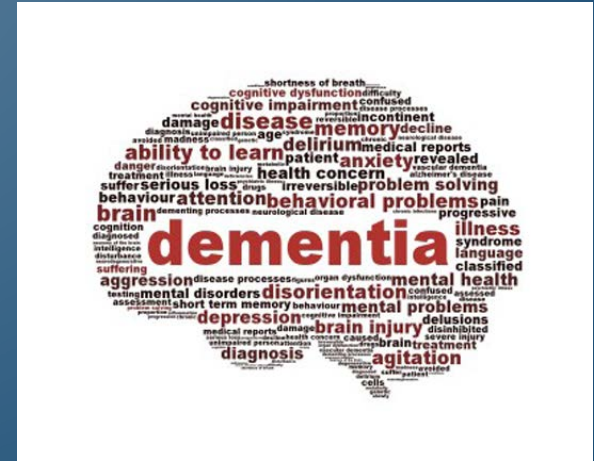
Dementia Care

Exchanging information & integrating services

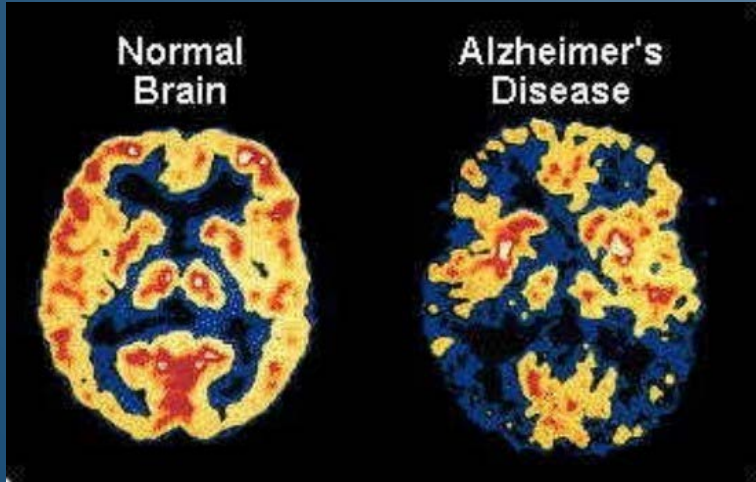
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DEMENTIA OVERVIEW

- Neurological damage with psychosocial factors
- Marked by cognitive deterioration, particularly impacting memory, communication, and judgment.
- Typically associated with the elderly, but early-onset dementia can impact individuals before the age of 65
- Broad category that encompasses many types of neurodegenerative diseases including Alzheimer's, Huntington's, and Parkinson's



Cognitive Impairment	Behavioural Manifestation	Functional Limitations
Memory	Personality, behavioural and mood changes	Self-care
Confusion		Activities of daily living
Concentration	Apathy	Balance and gait
Disorientation	Anger	Motor skills
Language	Anxiety	Visuo-spatial difficulties
Learning capacity	Sleep disturbance	
Judgement	Delusions	
Thinking	Hallucinations	
Comprehension	Physical aggression	
Calculation	Depression	
Time perception	Disinhibited social behaviour	



- 35.6 million people living with dementia worldwide
- Expected to double by 2030 and triple by 2050
- Annual global economic cost of dementia at \$818 billion (2015)
- Expected to rise to \$1 trillion in 2018
- Deemed a public health priority by the World Health Organization

IMPORTANCE OF SOCIAL CARE

- No current cure for dementia
- Social care fragmented because of varying individual needs
- Ranges from in-home care to assisted living facilities to full-time nursing homes
- Patients and families have a lot of autonomy in deciding on care
- Disease often progresses slowly, so advanced preparation of social care plan is critical



KEY CHALLENGES

1. Managing costs of social care
1. Promoting “positive aging”
1. Decreasing caregiver burden

1. MANAGING SOCIAL CARE COSTS

Reactive

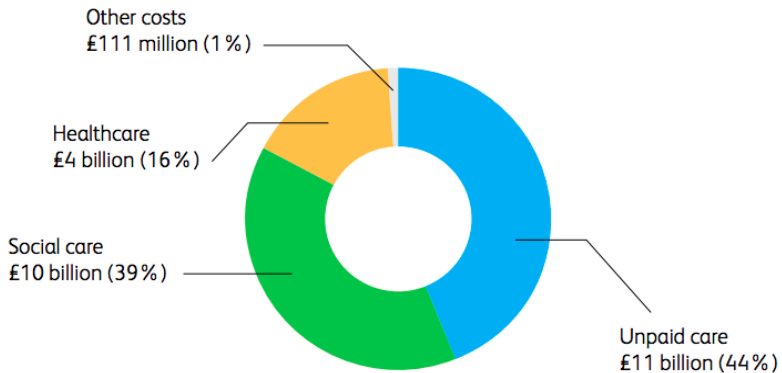
- Who shoulders the cost of dementia care?
- Policy changes to finance the social safety net for elderly

Proactive

- Poor integration of family caregivers, direct care workers, and community service agencies with formal medical care system = additional expense
- Minimizing antipsychotic drug prescriptions
- Encouraging advanced planning

This currently equates to over **£30,000** a year per person with dementia.

Figure 1 Cost of dementia care by location and type



2. PROMOTING “POSITIVE AGING”

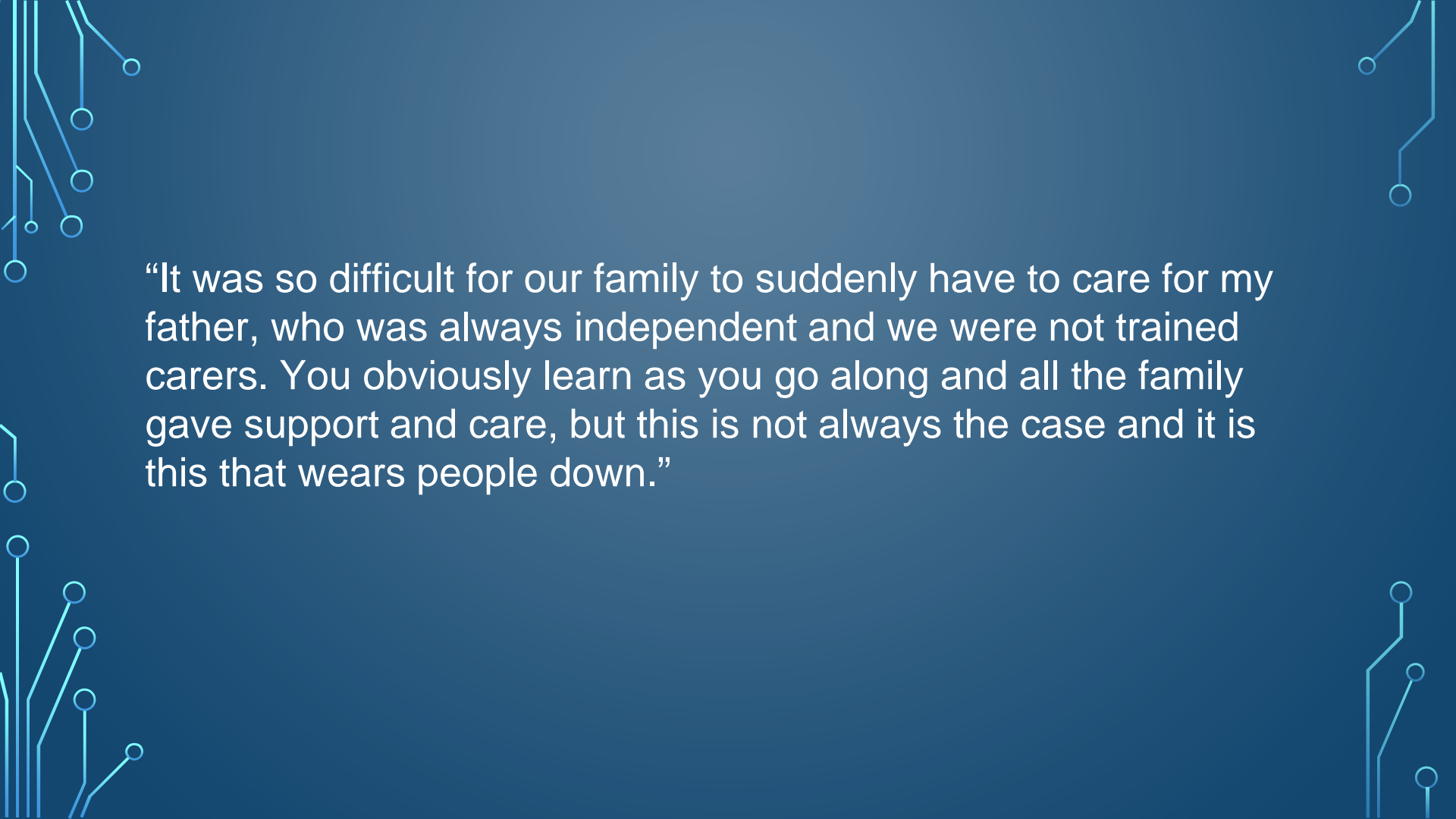


- Finding stimulating recreational activities for person with dementia
- Developing technologies that assist a person with dementia to live independently
- Avoiding anxiety for person with dementia
- Planning for the future and maintaining as much agency as possible

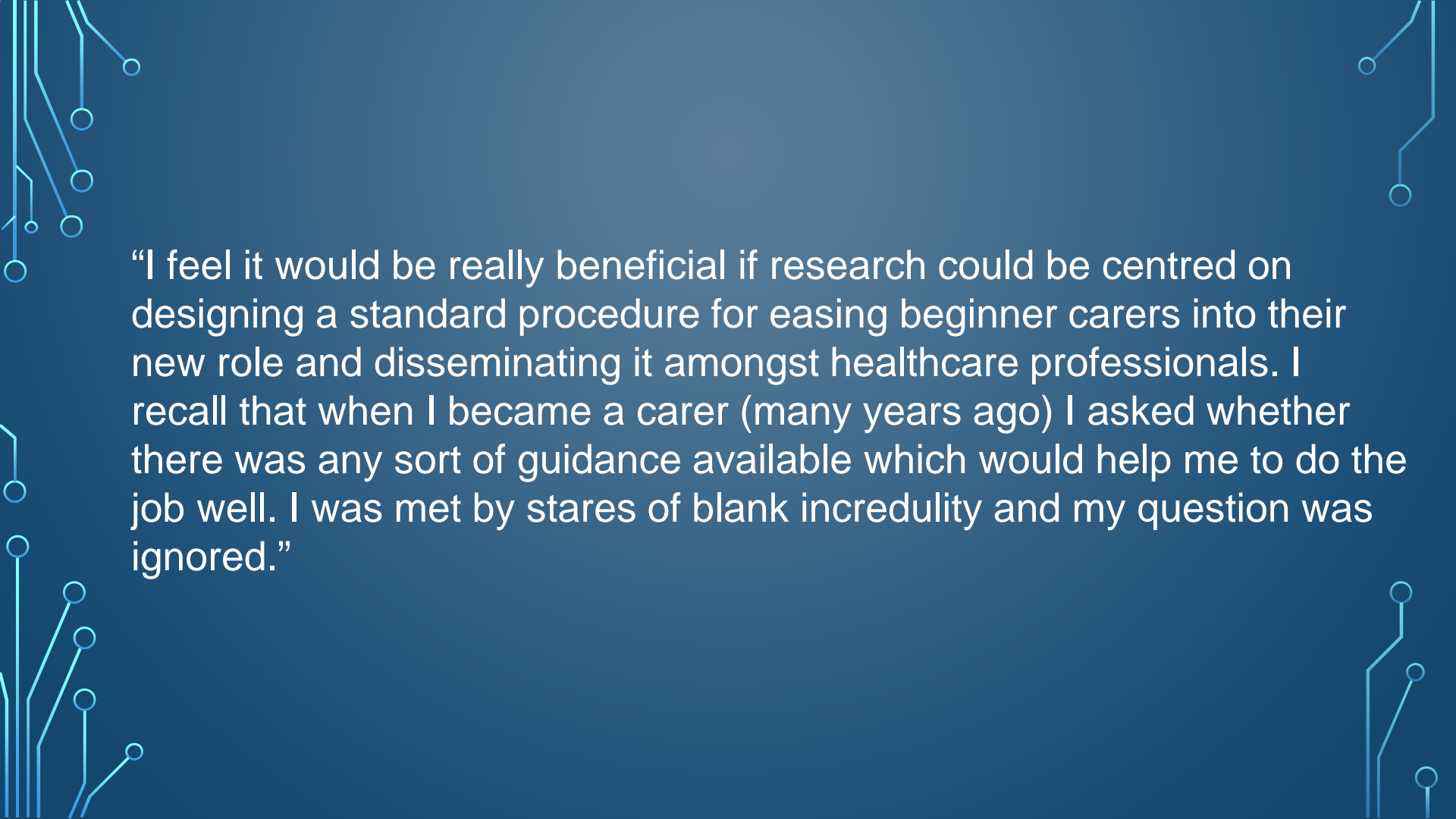
3. DECREASING CAREGIVER BURDEN

- Obtaining diagnosis
- Making informed decisions (e.g. at diagnosis, end-of-life)
- Ensuring good, person centred care (home, hospital, residential home)
- Accessing support to prolong caring at home
- Resolving communication problems between person with dementia and carers
- Managing physical symptoms (interrupted sleep cycle, incontinence, pain)
- Managing behavioural/psychological symptoms



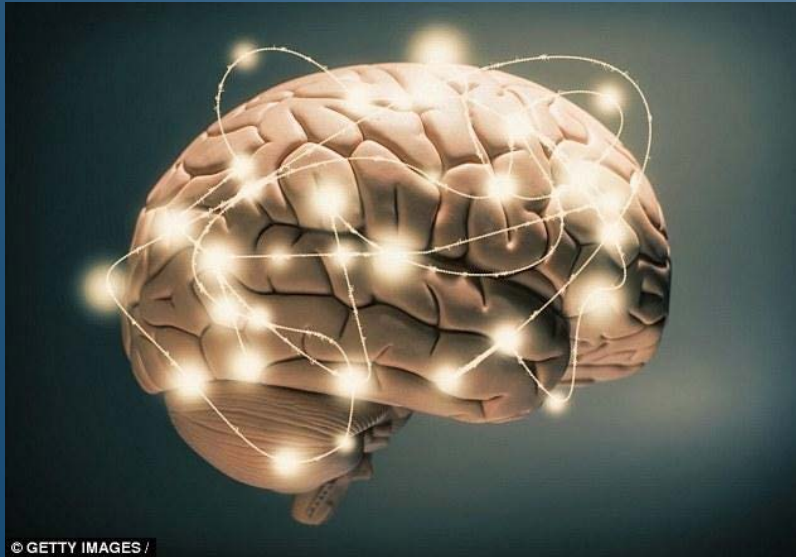
The image features a dark blue background with white, stylized circuit board traces in the corners. These traces consist of straight lines and small circles, resembling electronic components or connections. The traces are located in the top-left, top-right, bottom-left, and bottom-right corners, framing the central text.

“It was so difficult for our family to suddenly have to care for my father, who was always independent and we were not trained carers. You obviously learn as you go along and all the family gave support and care, but this is not always the case and it is this that wears people down.”

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“I feel it would be really beneficial if research could be centred on designing a standard procedure for easing beginner carers into their new role and disseminating it amongst healthcare professionals. I recall that when I became a carer (many years ago) I asked whether there was any sort of guidance available which would help me to do the job well. I was met by stares of blank incredulity and my question was ignored.”

THE NEED FOR INTEGRATED CARE



- ✓ Move from a reactive approach to a proactive approach
- ✓ Strengths across full spectrum of community, caregiver, or medical care
- ✓ Maximize synergies, reduce inefficiencies



WHY INTEGRATE CARE?

- A report by Deloitte and the UK think tank Reform (2017) found that: Almost half of people surveyed incorrectly believed that social care was free at the point of delivery. $\frac{2}{3}$ believed social care was provided by the NHS.
- Means tested

1. Systematic review by Sommer *et al.*, (2012)

- “The integration of health and social services is positively associated with clinical effects in the area of dementia care.”
- “Higher level of integration between the social and health services were associated with better outcomes.”

2. Recommendations outlined by the WHO Report on Dementia Care (2012)

- Integrated long-term care can delay admission to residential care and potentially reduce costs.
- Report also highlights the lack of knowledge of dementia care services among primary care providers, using the UK as an example.

POLICY TRANSFER EXAMPLES

France: MAIA (maisons pour l'autonomie et intégration des malades alzheimer)

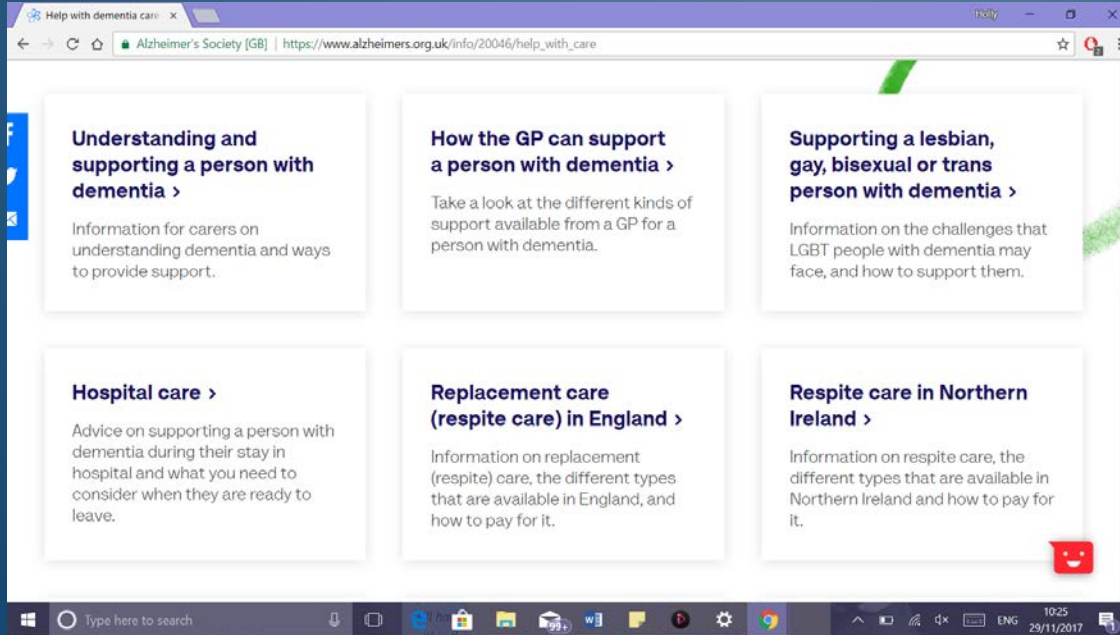
- Key component of the French Alzheimer's Plan
- Response to the fragmentation between the medical and social care sectors in France (Pimouguet *et al.*, 2012). Similar situation in the UK.
- Promotion of information sharing between hospitals, general practitioners, care centres, council services, social services, home workers, volunteers, dementia associations etc.
- One-stop shop
- Shift in focus: patient-centred.
- Effective? 15 trials have shown that it is effective at the regional level (WHO, 2012).

POLICY TRANSFER EXAMPLES

Australia: Local Area Coordinators(LACs) in the state of Western Australia

- Similar approach
- LACs: strong connections with the local communities. Provide support and advice to all, regardless of their needs or entitlement to funding (IPP, 2014). Similar in the UK, where social care is means-tested.
- Costs: staffing
- Tried in several communities in the UK.
- Evaluations in Australia, England and Scotland show that “the scheme delivers value for money, with key savings coming from diverting people away from more expensive crisis services” (IPPR, 2014)

POLICY LEARNING



The screenshot shows a web browser window displaying the Alzheimer's Society website. The URL is https://www.alzheimers.org.uk/info/20046/help_with_care. The page features six white cards with blue and green accents, each providing information on a specific topic related to dementia care. The cards are arranged in a 2x3 grid. The top row includes: 'Understanding and supporting a person with dementia', 'How the GP can support a person with dementia', and 'Supporting a lesbian, gay, bisexual or trans person with dementia'. The bottom row includes: 'Hospital care', 'Replacement care (respite care) in England', and 'Respite care in Northern Ireland'. The Windows taskbar at the bottom shows the date as 29/11/2017 and the time as 10:25.

Understanding and supporting a person with dementia >
Information for carers on understanding dementia and ways to provide support.

How the GP can support a person with dementia >
Take a look at the different kinds of support available from a GP for a person with dementia.

Supporting a lesbian, gay, bisexual or trans person with dementia >
Information on the challenges that LGBT people with dementia may face, and how to support them.

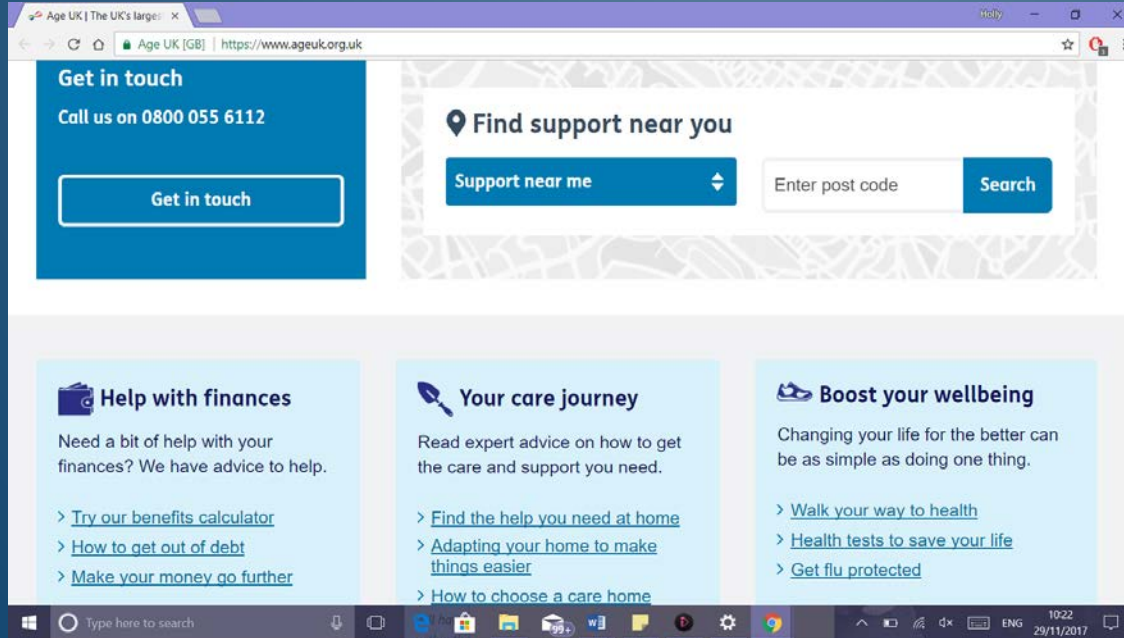
Hospital care >
Advice on supporting a person with dementia during their stay in hospital and what you need to consider when they are ready to leave.

Replacement care (respite care) in England >
Information on replacement (respite) care, the different types that are available in England, and how to pay for it.

Respite care in Northern Ireland >
Information on respite care, the different types that are available in Northern Ireland and how to pay for it.

Alzheimer's Society provides a advice targeted at families and informal caregivers.

POLICY LEARNING



Build on model of Age UK which provides a hotline and a satellite office location finder.

POLICY PROPOSAL

Establish a public-private partnership to co-develop an online information hub for dementia care decision making.

The hub would integrate:

- a. Public care (in the UK, councils fund means-tested care to a small section of the population)
- b. Private care (range of providers and settings)
- c. Programmes provided by charities and community groups

Features

One-stop, informed shopping

- Quality assessments prominently displayed in care search tool
- Easy comparison of options
- Setting standards and incentivizing performance improvement among care providers



Features

Planning for positive aging

- Log-in to save choices
- Create a custom care plan (automatically calculates cost of care and generates financial planning advice)

Assign care tasks

- Choose tasks from drop down menu
- Central tracker of who is doing what and when
- Reminders sent to person with dementia, caregiver, and/or hired help

“Ask for Help”

- People with dementia and their carers can communicate directly with public and nonprofit social service providers

Multiple-user collaboration

- Allows GPs, Specialists, and other carers (if granted permission) to review individual accounts and make suggestions

IMPROVING ON EXISTING PLATFORMS

Provide information about **dementia-specific care**

- a. Primary care providers currently lack knowledge of dementia care (WHO report).
- b. In the UK, around a third of care homes with dedicated dementia provision report having no dementia-specific training for staff.
 - Improving management of behavioural and psychological symptoms of dementia using non-pharmacological techniques
 - Reducing over prescription of antipsychotic medications
 - Partnering with dementia care charity to provide online training materials

Not just providing information, but also **building a communication network**, encouraging information sharing between different stakeholders to improve care

- a. Consolidated hub for many different stakeholders (e.g. people with dementia, healthcare professionals, and other care providers)
 - Simplify care planning and coordination

IMPLEMENTATION BARRIERS

Getting stakeholders buy-in for the information hub concept

- Problem: Difficult due to range of providers/stakeholders and decentralised health and social care
- Strategy: Public-private partnership to co-develop the hub, reconciling different motivations

Low understanding of how to access and use the hub

- Problem: Getting a less tech-savvy, older demographic to use the hub
- Strategy: PPP stakeholders make institutional commitments to promote the information hub (E.g. AgeUK support network introduces potential users to the hub and provides instructions for use)



DEMONSTRATING VALUE TO STAKEHOLDERS

- Integrated, informed care decision making

- > care is higher-quality and/or better fit to individual needs
- > better outcomes for those with dementia and less burden on caregivers

- Emphasize mutual benefits

- People with dementia: Greater agency, empowerment
- Carers: Decision support, value for money
- Government/NHS: Improves effectiveness of public health strategy, reduces costly inefficiencies, surveillance opportunity
- Private charities and care providers: Greater exposure in target market

- Regional pilot as proof of concept

- Collaboration with a university and an NHS Trust



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From a private sector UK provider of dementia-specific nurses, but gives a useful overview of different sources of financial support/ information: <https://www.dementiauk.org/wp-content/uploads/2017/07/Sources-of-support-WEB-June-17.compressed.pdf>

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