Opportunities for supporting people with dementia and their caregivers at home

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## Developments in assistive technology

(www.atdementia.org.uk)

### Reminders
- PivoTell
- Loc8tor

### Orientation
- ENABLE Project

### Safety
- BIME

### ADL support
- Ambient Kitchen, Culture Lab, Newcastle University
Opportunities for support: Professional carer perspective

Opportunities for support: Patient-caregiver perspective

Issue of novelty

Issue of novelty

Opportunities for support

Opportunities for support

Underlying Deficits
- Sequencing: Sequence; Ordering
- Memory/Orientation: Forget things; Forget to do things
- Learning: Appliances

Problems in the Home
- Daily Activities: Dressing; Medication
- Risks: Cooker safety
- Interpersonal: Communication

Consequences
- Patient: Physical Wellbeing, Safety; Security; Health
- Caregiver: Relationship, Care Demands

Situated Factors
- Verbal Cues: Prompts, Notes
- Visual Cues: Display items, Items visible
- Familiarity: Appliances, Surroundings, Routine

Underlying Deficits
- Sequencing: Formulate procedures, becomes motionless
- Memory/Orientation: Forget to do things/Events, Locating items; Knowing the time; Finding their way

Problems in the Home
- Daily Activities: Dressing; Medication
- Domestic: Washing-up, Locking-up
- Leisure: Lose Interests

Consequences
- Patient: Physical Wellbeing, Safety; Security; Health
- Caregiver: Relationship, Care Demands

Aim: Understand how social engagement and support can mediate health outcomes and reduce risks of loneliness and depression in older adults.

Example project: Building Bridges

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Colette Garry

Phase 1
Understand Problem

Phase 2
Develop Concept

Phase 3
Explore requirements

Phase 4
Refine
Supporting the caregiver

Prevalence
Estimated (2000) 25 million people worldwide with dementia
1 in 20 over 65; 1 in 5 over 80 (Prince and Knapp, 1997)

63.5% live at home

One report estimated that dementia in the UK cost £14 billion in 2009; Caregiver contributions saved £5 billion (House of Commons Public Accounts, 2009)
Supporting the caregiver

Caregiver burden
The role can lead to elevated levels of depression, stress and social isolation (Hoskins et al., 2005; Venables et al., 2006)

Estimated 50,000 carers in Ireland
-75% report upset due to behavioural problems
-33% completely overwhelmed by caring role
-73% disruption to sleep
-79% report physical strain

Perceived ability to cope is a strong predictor for patient referral into institutional settings (Hope et al., 1998)
Example ICT for caregivers

ComputerLink (Casper et al., 1995)

CTIS: Computer Integrated Telephone System (Czaja, 2002)

ALZONLINE (Glueckauf, 2004)

CARING FOR OTHERS (Marziali, 2006)

DEM-DISC: DEMentia-specific Digital Interactive Social Chart (van der Roest et al., 2010)
**TRIL caregiver project**

**Aim:** Explore how ICT can support social and mental health of caregivers living with a person with dementia

**Sample:** Spouse caring for person with mild-moderate dementia at home

**Method:** Home visit interviews and Grounded Theory Analysis (Strauss and Corbin, 1990)
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<th>Theme</th>
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<td>Educational</td>
<td><em>Information and new developments; Managing change; Services and local projects</em></td>
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<td>Informal</td>
<td><em>Practical support; Outlet; Mentoring and reassurance;</em></td>
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<td><strong>Social Isolation</strong></td>
<td>Going out</td>
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<td>Sustaining network</td>
<td><em>Patient withdrawing; Guilt</em></td>
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<td><strong>Relationship</strong></td>
<td>Disappearance</td>
<td><em>Personality change; Dependence</em></td>
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<td>Interaction</td>
<td><em>Communication; Interests</em></td>
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TRIL caregiver project

Education

“I find that there’s not a lot of information in the public domain for...nothing in the papers about it”

“So many bits of it to be put together, like an enormous jigsaw, but the only difference is that the pieces keep changing”
TRIL caregiver project

Informal support

“**You have to offload something but you don’t want to be the one that, here she comes...you can’t spend the whole time talking about it**”

“I **don’t want to drag attention to it because it probably would upset him. If he knew that they know”**

“**Reassurance to know that there are other people in that boat**”
Difficulty leaving the house

“I’ve to stick with that routine and get her ready to go and collect her in the evenings. So I can’t just breeze off”

“I better not go out because I was afraid of her, she did fall two or three times now, just fell down”

“If we were in a supermarket or a department store and I go somewhere, it’s just a moment, a split of a second and she’s gone”
“She became over a period of 4 or 5 years, distant from some people that she was quite friendly with”

“She says she has no friends but, sometime she doesn’t want to go out, and she forgets that”

“If she’s in here on her own, she gets a bit depressed. And she wouldn't’ go out...sometimes I do feel guilty about going out”
Relationship

“I’m not inclined to say much to her, I will involve her, but two minutes later she’s forgotten”

“She’s no interest in the telly. She’d be sitting here, looking up this way but the television is over there.”
Relationship

“She’s beginning to remember her old life now because she can’t rely on the present...so I’d take out the old photographs, from when we were married”

“We sat in the shade watching the sea-lions, children and all that, she likes where there’s activity going on and she can watch”
TRIL caregiver project

Relationship

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“We sat in the shade watching the sea-lions, children and all that, she likes where there’s activity going on and she can watch”
Conclusion: Requirements for ICT to support caregivers

- Customised educational content (about dementia, services and self-care)
- Maintain support networks (existing and peer-support)
- Social
- Flexible (time and place)
- Support patient-caregiver interaction
- Involve potential users throughout concept development and design