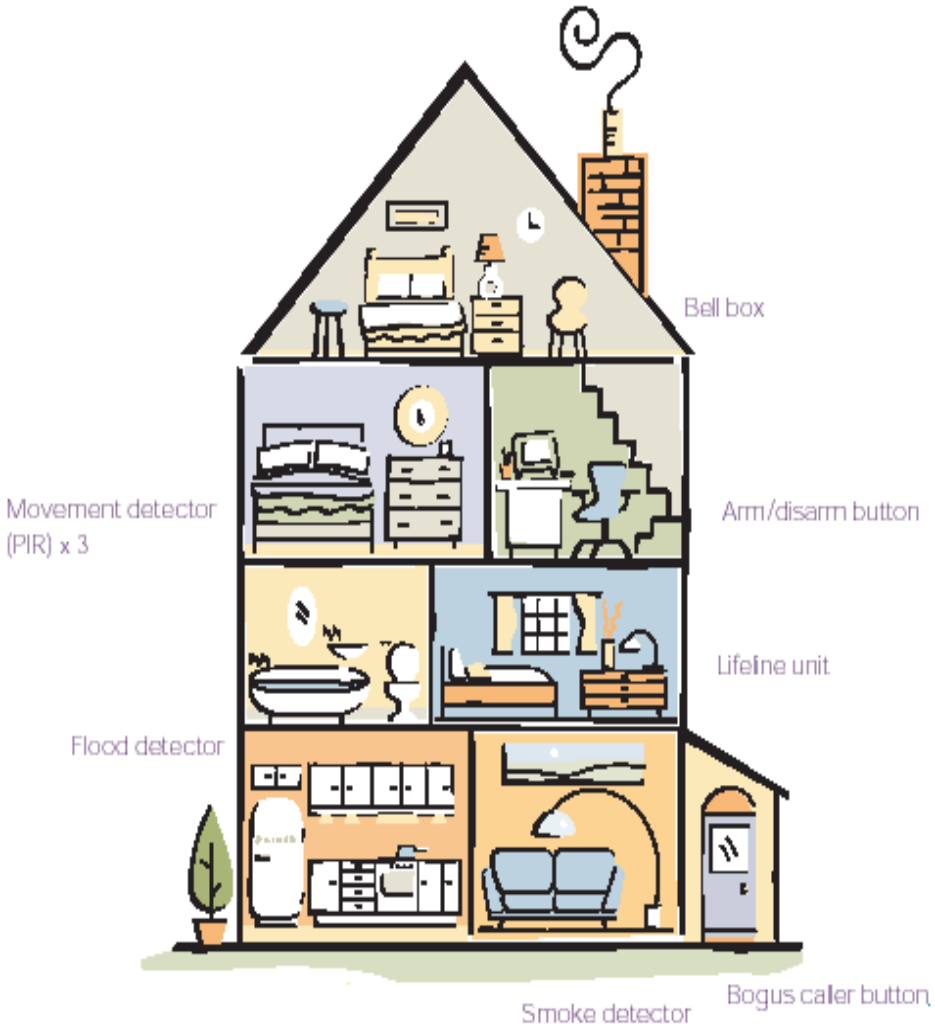


Assistive Technology, Telecare and Telehealth for people with dementia and their Carers

Stephen Wey

Learning outcomes

- To be aware of the potential role of assistive technology in supporting **people** with dementia in their own homes or care settings
- To be able to identify examples of assistive technology (AT), telecare and lifestyle monitoring applications and devices
- To have critically engaged with ethical and practice issues in relation to the assessment and provision of assistive technology

Uses of technology - definitions

- Assistive technology
- Telecare
- Life style monitoring
- Telehealth
- Telemedicine
- **Tele-rehabilitation**

Telehealthcare
Umbrella term
used since 2010

NB: Tele = “over a distance” – e.g. telephone, television

What is Assistive technology

‘The phrase ‘assistive technology’ is used to describe products or systems that support and assist individuals with disabilities, restricted mobility or other impairments to perform functions that might otherwise be difficult or impossible.’ Gov.uk 2024

https://www.gov.uk/government/publications/assistive-technology-definition-and-safe-use/assistive-technology-definition-and-safe-use

What is Assistive technology

- An umbrella term which includes a wide range of devices from simple low-tech items to sophisticated high-tech integrated systems

‘any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed’ (Royal Commission on Long-term Care 1999).

This is also the definition used in A Dictionary of Social Work and Social Care (2 ed.)

John Harris and Vicky White

Who uses Assistive Technology?

Hands up!

…in the context of dementia rehabilitation

‘It is best seen as an extension of the aids and adaptations provision beyond static pieces of equipment’

Marshall, 2003

…in the context of dementia rehab

- To facilitate improved **confidence** in carrying out daily activities
- To facilitate meaningful **occupation** and the maintenance of valued social **roles**
- To support the persons **memory, orientation** and other **cognitive abilities** that are central to everyday life
- To help maintain the persons **safety** without infringing on their **human** rights
- To **support** and **reassure** carers

Common issues

- Occupational and social deprivation – maintaining meaningful activities and social contact
- Lack of control over environment
- Loss of confidence or self efficacy
- Safety using appliances – risky actions
- Forgetfulness - disorientation
- Going out at ‘inappropriate times’
- Getting lost - outside or inside
- Community vulnerability e.g. Distraction burglary
- Leaving taps running, flooding
- Falls, acute illness, accidents
- Neglect of health and well-being – diet, hydration, medication, body

‘Assistive technology’ may include:

- Daily living aids and equipment (including for mobility)
- Technology to promote social contact and participation
- Electronic assistive technology (EAT)
- Environmental control (EC) systems
- SMART technology – when used to enable people to overcome barriers to participation

- Not necessarily sophisticated **high tech** gadgets and computerised systems
- Many **assistive technology** devices are used as **standalone devices**
  - **Some examples**
- However, some electronic devices can be wirelessly linked to enable care and support and help manage risks via **information and communication technology (**ICT)
  - **-> telehealthcare**

Sensorcare

These are all examples of devices that can be wirelessly interlinked and networked (e.g. as part of a telecare service)

Telecare

- Telecare describes any service that brings **health and social care** directly to a user, generally in their homes, **supported by information and communication technology.**
- It covers social alarms, lifestyle monitoring and telehealth
  - https://www.tsa-voice.org.uk/consumer-services/what-is-telecare
- 3 “Generations”

Social Alarms

- **‘1st generation’ telecare**
- **Social alarm systems** have been around for over 40 years and are in the homes of over 1.6 million users in the UK (Audit Commission 2006)

‘2nd generation’ Telecare package

Temperature and gas sensors

Medication aid

Service user

Flood detector

PROTOCOLS

Nominated telecare responders

Lifeline pendant

Door use and entry

Falls / bed chair sensors

Care-plan

MDT

OT

Assessment

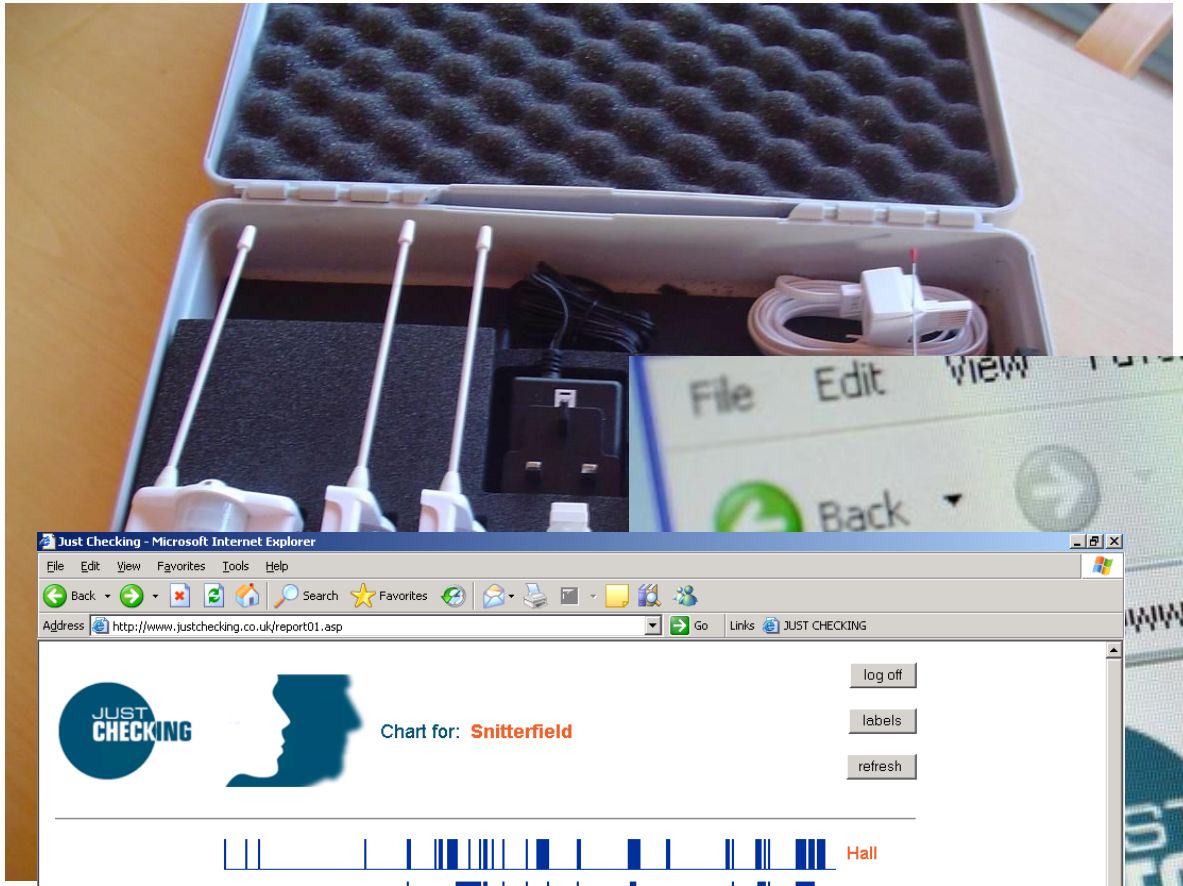
Response services

From reaction to prevention

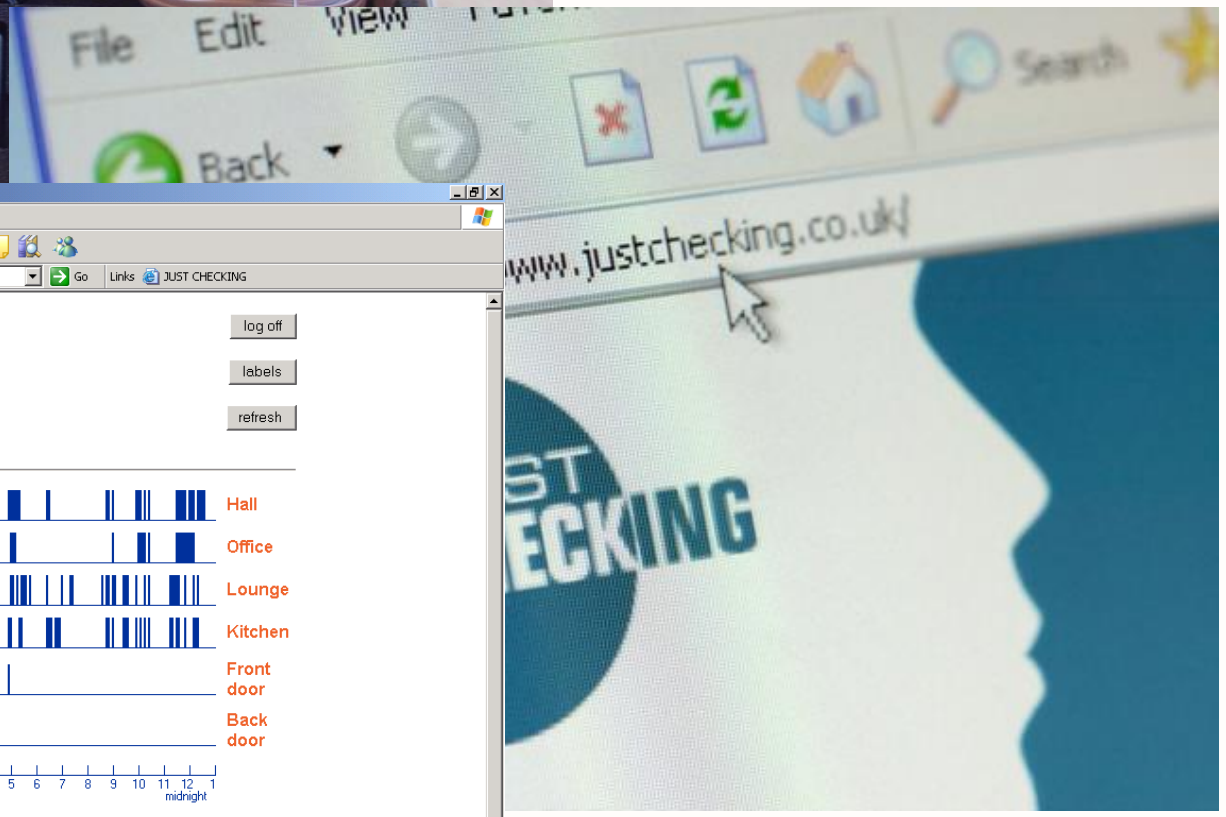
- Kinsella (2010) argues we need to shift from reactive detection technologies to prevention technologies.
- **Reactive technology** – pendant alarms and pull cords, falls sensors, pressure mats for bed/chairs, telecare risk sensors – mainly react after an event has occurred
- **Preventative technology** – monitoring or promoting health and well being or enabling management of treatable/preventable risk factors (person or environment)
  - + improving self efficacy and self management
  - e.g. lifestyle and activity monitoring, telehealth for treatable risk factors, telerehabilitation

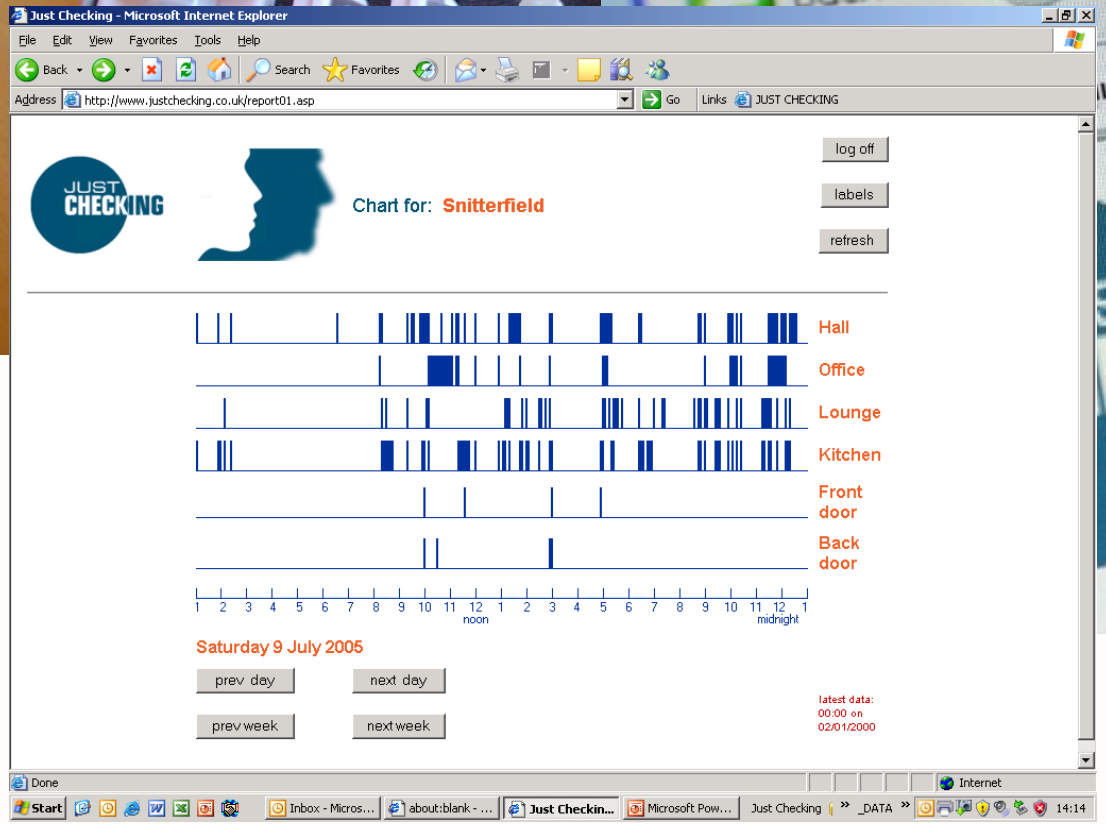
Life style monitoring & support

- **3rd generation' telecare**
- A proactive approach based on monitoring a person's pattern of activities 24/7
  - Compares current behaviour to a baseline derived from prior assessment & carer knowledge
- Aims to anticipate problems before they become crises
  - And to monitor well being and performance
- e.g: Just Checking




JUST
CHECKING


File
Edit
Back
Search
www.justchecking.co.uk/
JUST
CHECKING


Just Checking - Microsoft Internet Explorer
File Edit View Favorites Tools Help
Back Search Favorites
Address http://www.justchecking.co.uk/report01.asp
Go Links JUST CHECKING
JUST CHECKING
Chart for: Snitterfield
log off
labels
refresh
Hall
Office
Lounge
Kitchen
Front door
Back door
1 2 3 4 5 6 7 8 9 10 11 12 1 2 3 4 5 6 7 8 9 10 11 12 1
noon
midnight
Saturday 9 July 2005
prev day
next day
prev week
next week
latest data:
00:00 on
02/01/2000
Done
Internet
Start
Inbox - Micros...
about:blank - ...
Just Checkin...
Microsoft Pow...
Just Checking
_DATA
14:14

Leeds evaluation

- During a 12 month pilot in the Leeds Mental Health Intermediate Care Team and a Community Mental Health Team, Just Checking was used for assessment in 55 cases.
- The teams concluded that use of Just Checking improved the quality of the assessment and the outcomes for the service user.
- **Generally people with dementia were managing at home better than expected.**
- Objective data from the system helped to challenge preconceived fears
  - Interventions could concentrate on supporting the capabilities of the person, in effect giving them a voice in decisions about their care.
- ‘Timely’, ‘cost effective care’ ‘promoted independence’ ‘improved the opportunity to be supported at home’ rather than being admitted to hospital or residential care.

Mainstreaming technology – SMART homes & SMART Phones

- **Environmental control systems** enable control of the whole home environment – this could include:
  - Opening/locking doors
  - Opening and closing curtains and windows
  - Controlling the ambient environment
  - Controlling appliances
  - Contacting others
  - Automating shopping
  - Safety monitoring
- Traditionally Environmental control systems have required specialist assessment and provision as assistive technology
  - This is still the case for many people with disabilities

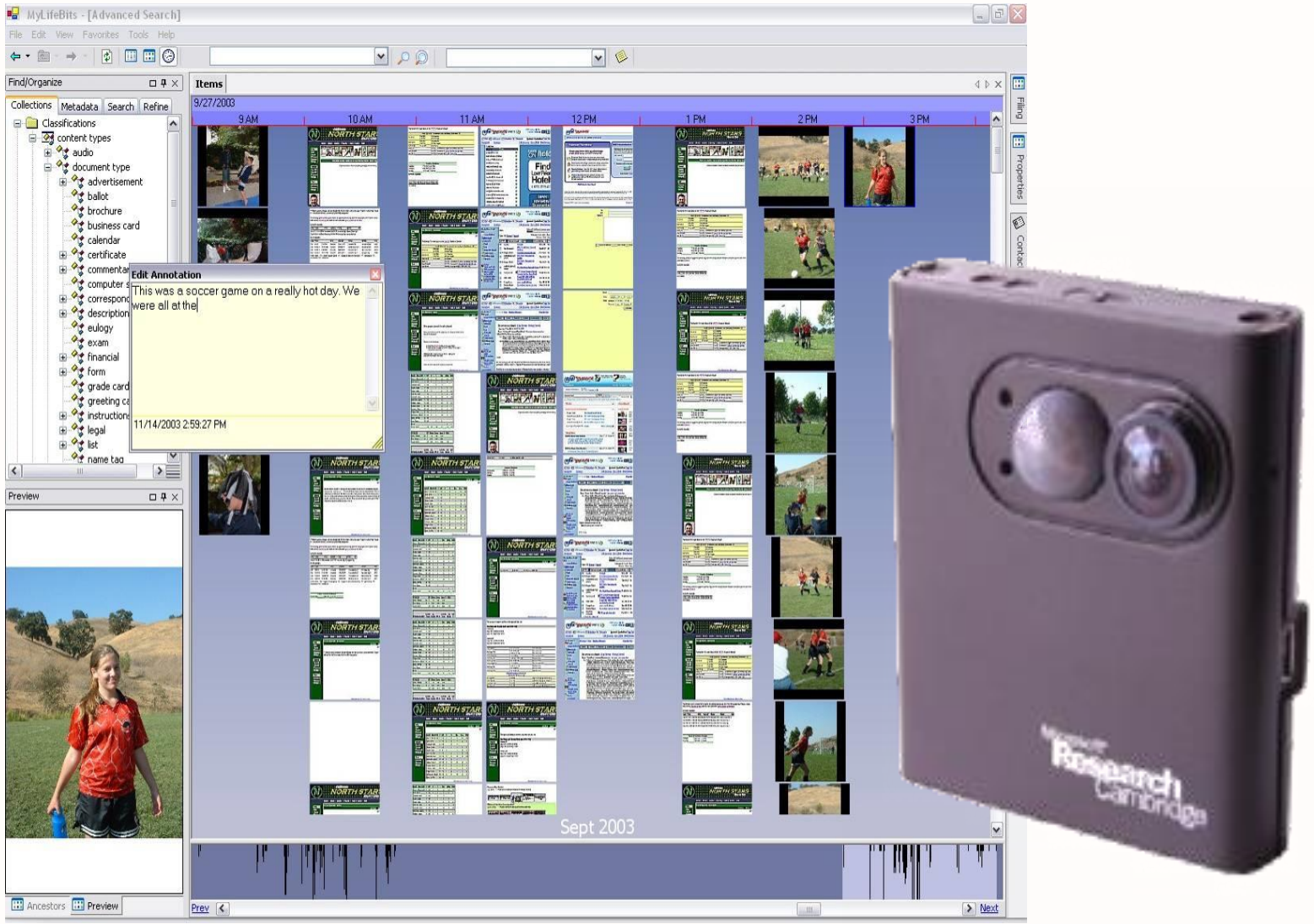
Mainstreaming technology — SMART homes & SMART Phones

- However, in the last few years we have seen the **mainstreaming** of many forms of environmental control in the form of systems like HomeKit and Amazon Echo
- The positive is that this reduces stigma and places control into the hands of consumers
- Costs coming down but initial costs can be expensive
- It is also not based on specialist assessment of needs which may result in less individually tailored solutions for some (although possibly more for more informed users)

Assistive technology for participation and enablement

- Several authors have critiqued the ‘surveillance’ and ‘risk’ focus of telehealthcare technology (Wey, 2004, Astell, 2005) and Baldwin, 2006)
- Aim not just to monitor people but to actively assist in activities of daily living (e.g. COACH - hand washing), communication, interaction, and leisure occupations (e.g. reminiscence) (Astell et al 2019)
- Enabling meaningful activity, participation, social and cultural inclusion

Life Logging



Sensecam with lifelogging Software

SenseCam – a cognitive support for life logging

- https://www.microsoft.com/en-us/research/project/sensecam/alleviating-memory-loss/
- https://pubmed.ncbi.nlm.nih.gov/28124633/

Research findings - LifeLogging

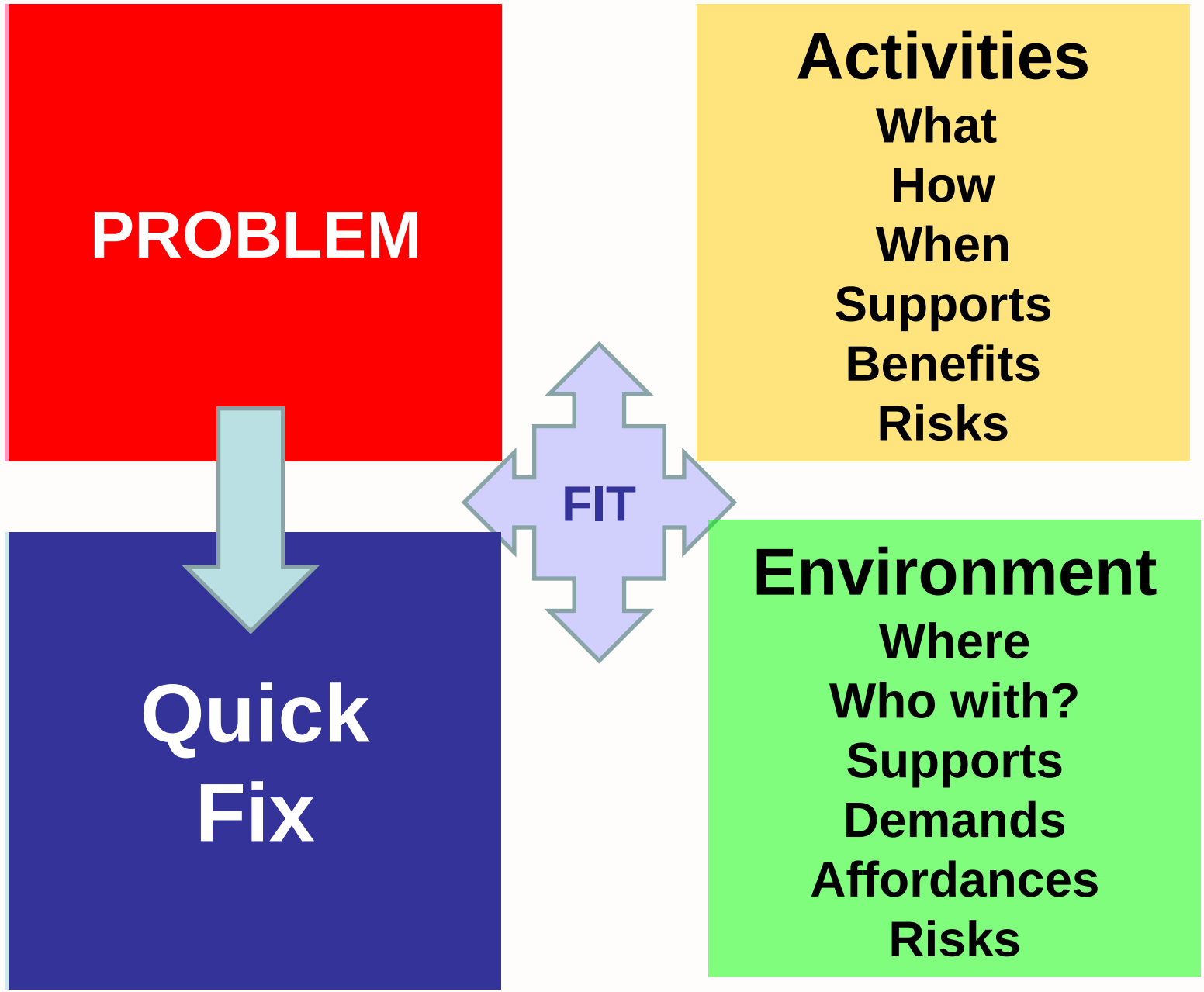
- Camera was far more successful in activating memories of past events than had been anticipated (Piasek, Irving & Smeaton, 2011)
  - Acquired cognitive impairment, dementia
  - As compared to written diaries and calendars
- Evidence from Lifelogging suggests people with memory problems may be able to take in and store more information, than previously believed – often subliminally
  - But are having difficulty retrieving and using it
- **Importance of active memory building involving carer**
- Piasek, Irving & Smeaton (2011) describe an innovative intervention strategy combining use of the Sensecam with Cognitive Stimulation Therapy (CST) to facilitate personhood and cognition

Augmented reality for orientation

- https://dl.acm.org/doi/fullHtml/10.1145/3463914.3463918
- https://jneuroengrehab.biomedcentral.com/articles/10.1186/s12984-019-0530-z

Person Centred Assessment

For Assistive Technology


PROBLEM
Quick Fix
FIT
Activities
What
How
When
Supports
Benefits
Risks
Environment
Where
Who with?
Supports
Demands
Affordances
Risks

Assessment for assistive technology and telecare

- Guy Dewsbury (Sommerville & Dewsbury, 2007, Dewsbury and Linskell, 2011) argues that two contrasting methods of Telecare (& Assistive technology) assessment have emerged within services:
  - **Technology Focused** or
  - **Person-Centred**.
- **Technology focussed assessment** starts with the premise that the person is being assessed for Telecare and follows a simplistic formula of matching the person's needs (generally identified as risks) to what is available: Available Telecare equipment + Risk (floods, falls, dementia etc) = Telecare solution

Person centred assessment

- In contrast **Person centred assessment** starts from the person's own perceptions of need, goals and expectations, and takes into account the person's strengths and skills, as well as their daily activities, lived environment and social relationships. (Sommerville & Dewsbury, 2007, Wey, 2004)

Matching AT to the person (not the other way round)

- Matching assistive technology to person in practice
  - Professional reasoning to support and justify intervention
  - Contexts – policy, guidelines, legislation, evidence base
  - Person centred assessment and analysis to identify fit to person, daily activities and routines and environment
  - Person centred practice context
    - strengths led
    - **consider scope for skills acquisition or restoration**
    - **positive risk management - enablement not containment**
    - capacity and consent
    - critical thinking (Steils et al, 2021)
    - **Collaborative practice involving person and carer to 'make it work for them' - assessing and adjusting 'fit' dynamically(Gibson et al 2019)**
  - Reflection and supervision - consider alternative options
    - just as important to consider **when not to** use assistive technology

Phyllis

- Currently on assessment ward for people with dementia
- Has Parkinson’s disease
- Mild to moderate memory problems identified
- Has been found outside the house at night by neighbours on a ‘few’ occasions
- Family feel she should be in care
- Phyllis does not
- You are part of the team assessing Phyliss - what will you do?

External cues

Telecare

Social support and/or care

Do nothing technological - Work with Phyllis to identify drivers of going out at night and meet needs (e.g. social, anxiety, nighttime orientation, promote sleep, adjust medication)

Assessment/intervention models

Provide a 'lens' through which to analyse person and situation and guide professional reasoning

- Person - Environment
  - Lawton, Kahana - Models of Person-Environment fit
- Person - Technology
  - Baker/King – Ergonomic Equation
  - Scherer, M - Matching Person and Technology Model
  - Rogers and Holm - AT device user prediction model
- Person - Environment - Occupation
  - Law - Person-Environment-Occupation model
- Person - Activity - Environment – Technology/Solution
  - Ballinger and Winchcombe - Trusted Assessor model

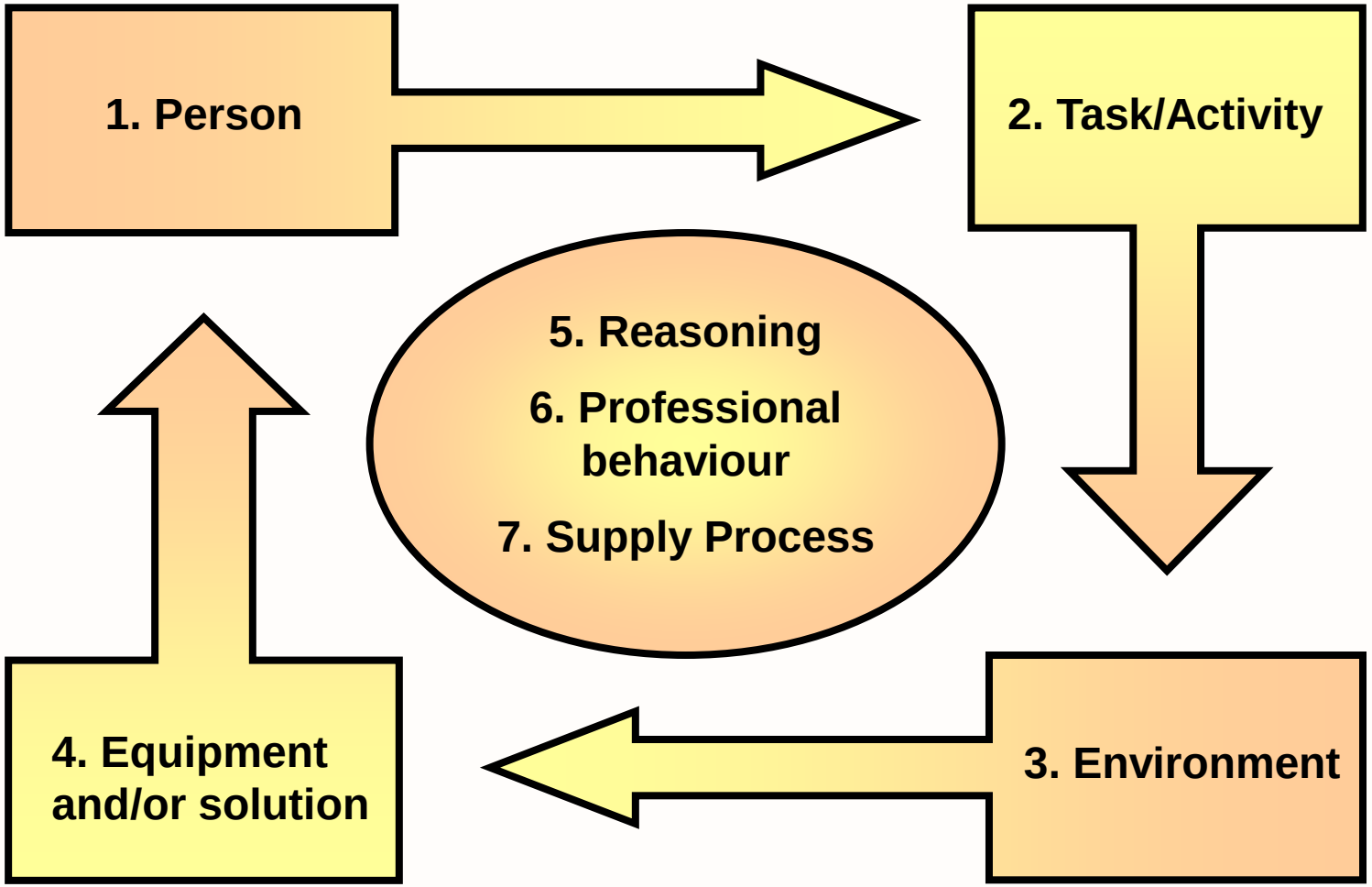
Satterfield, 2016

Matching person and technology (MPT) model

- A consumer-led, person-centred process used to match individuals with technological solutions
- Comprises a series of questionnaires that consider:
  - The environment (M = Milieu)
  - The users preferences (P = Person)
  - and the functions and features of the device or solution (T = Technology)

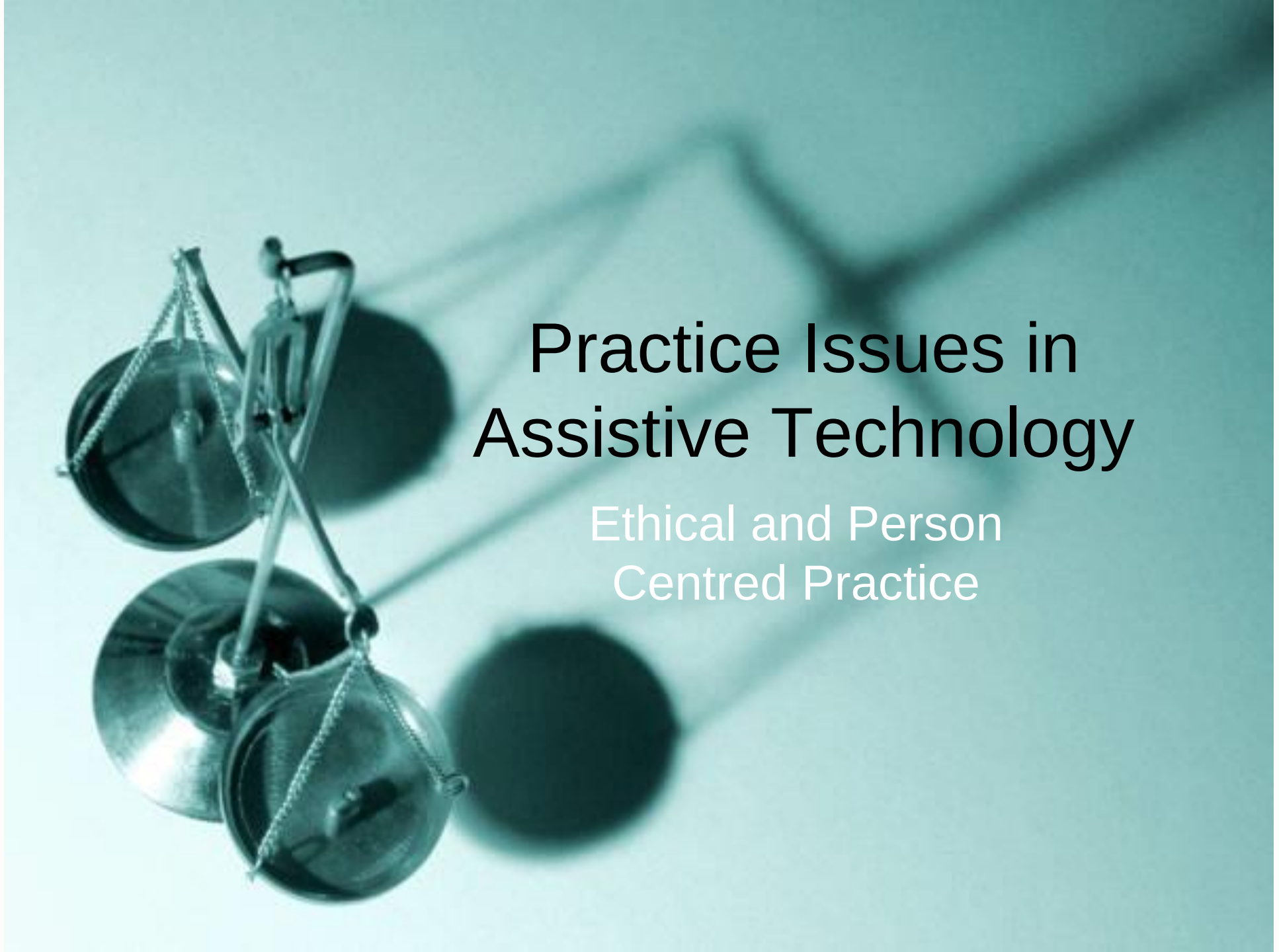
    » *Scherer, et al. Institute for Matching Person and Technology (2002)*

- A good assessment matches a person with a particular set of needs/situation to the best assistive technology and usually requires more than one evaluation
- Each **assessment process** explores specific things based on the individual's needs which may include augmentative communication, mobility, environmental control, recreation, support and assistance, security or computer access
- No one person can do an assessment for all needs, so a team of specialists is usually required (OT, PT, SLT, SW)
  - the user and any carers are seen as core expert members of this team
- All team members work closely with one another and each team member makes a unique contribution
  - Not all specialists need to be available for a particular assessment



A practice model to inform competencies in providing equipment

Ballinger & Winchcombe 2005



Practice Issues in Assistive Technology

Ethical and Person Centred Practice

Containment or enablement?

"Technology… is an odd thing. It brings you great gifts with one hand, and it stabs you in the back with the other"

C.P. Snow

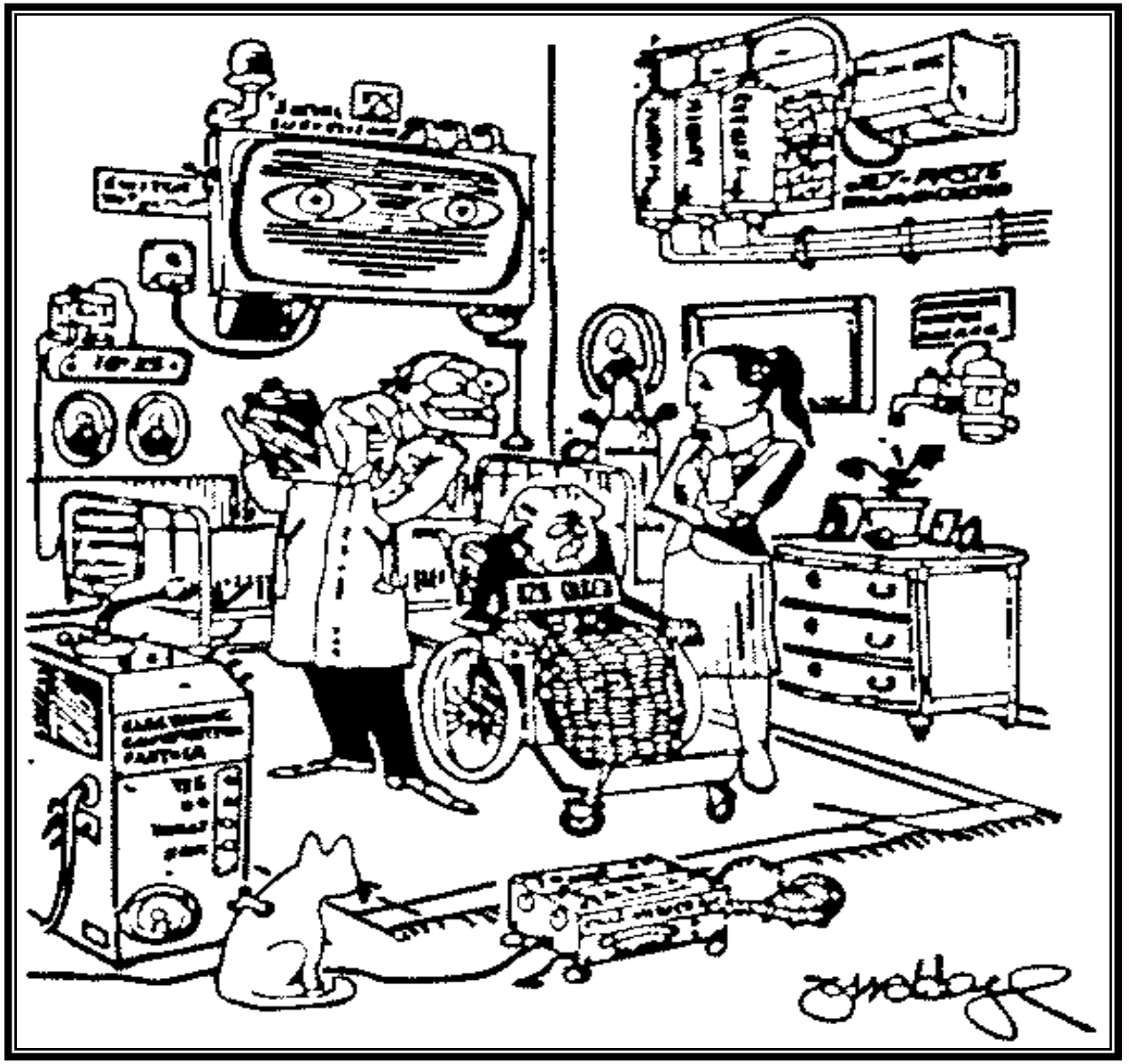
Reflections on ethics, dementia and technology (Baldwin, 2006)

- ‘The use and development of technology is **morally ambiguous.** Even when ethical values are consciously embedded within the design of a technological device, there is always a cost involved, something is lost or displaced’.

– Baldwin, 2006

Ethical ‘costs’ posed by technology

- Erosion of human contact
  - Human contact being replaced or solely mediated by technology
  - Depersonalisation and alienation
- Disempowerment and/or neglect of ability and personhood
  - Creation of over complexity
  - One sided focus on risks, problems, disability



…and thanks to the electronic surveillance we only need a home help every half year to adjust the generator

A balancing act

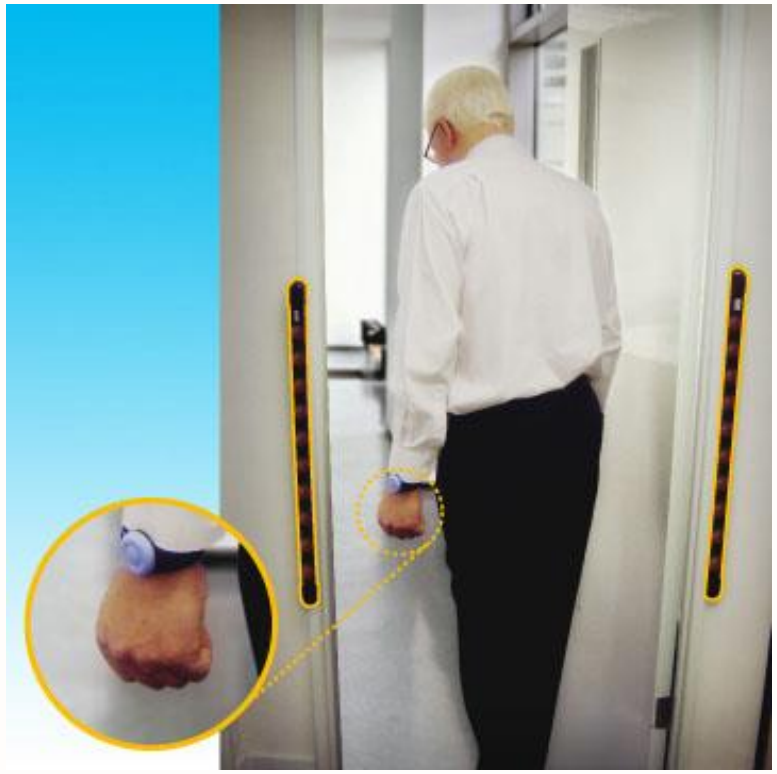
Balancing the needs of people with dementia and their carers can be difficult, especially when it comes to safety versus freedom. Many an anxious carer has resorted to locking doors to prevent the person they care for going missing. The introduction of safer walking technologies is one way of addressing both sets of needs, but these bring with them a host of other issues.

Safer walking technologies, commonly referred to as electronic tagging or assistive technology, are aimed at improving the quality of life for people with dementia and carers. While having the freedom to walk is a basic right and can be a therapeutic experience for people with dementia, it can become problematic when safety is a concern... Having a device that would reduce carers' worry and give people with dementia greater freedom and independence seems like a good solution. But the use of such technology is a contentious and emotive issue.

What are safer walking technologies?

These are systems that have been developed to help people to live more independent lives. There are two types of technology which can be used.

- An alarm system – sometimes worn as a wristband – alerts carers when an individual has moved outside a set boundary. It cannot locate an individual, however.
- Tracking devices – global positioning systems for example – can locate a person at any time or place. These systems, which can resemble a small mobile phone worn by the person with dementia, are becoming increasingly available*.



- **Discussion points:**
- **In relation to technology used to monitor or track people with dementia when out and about**
- What are the potential costs and benefits for:
- Service users
- Carers
- Services?

“Costs”

- Doesn’t prevent all risks (e.g. road safety, vulnerability) and increases some:
  - Occupational deprivation
  - Loss of skills
- Potential to contribute to sense of powerlessness or of being watched
- Ethics of “containing” or restricting person
  - Erosion of personal locus of control and agency
  - Erosion of privacy
  - Infantilisation
  - Consent issues
- Potential for misuse
- Not looking at person as a whole
  - Fostering over-emphasis on negatives or problems

“Benefits”

- Enabling people to walk and maintain activity levels
- Maintenance of skills e.g.
  - mobility
  - locating and route-finding
  - problem solving
  - Orientation
  - memory
  - road safety/risk awareness
- Occupation and stimulation (quality of life)
- Maintaining confidence and self efficacy
- Community participation and social inclusion
  - Helping person to stay in own home
- Reassurance for carers

- *Baldwin argues we should ask ourselves, “does the situation call for a technological solution”?*
- *“The problem of ‘wandering’, for example, does not necessarily call for greater technological surveillance but could be addressed through the availability of walking companions.”*

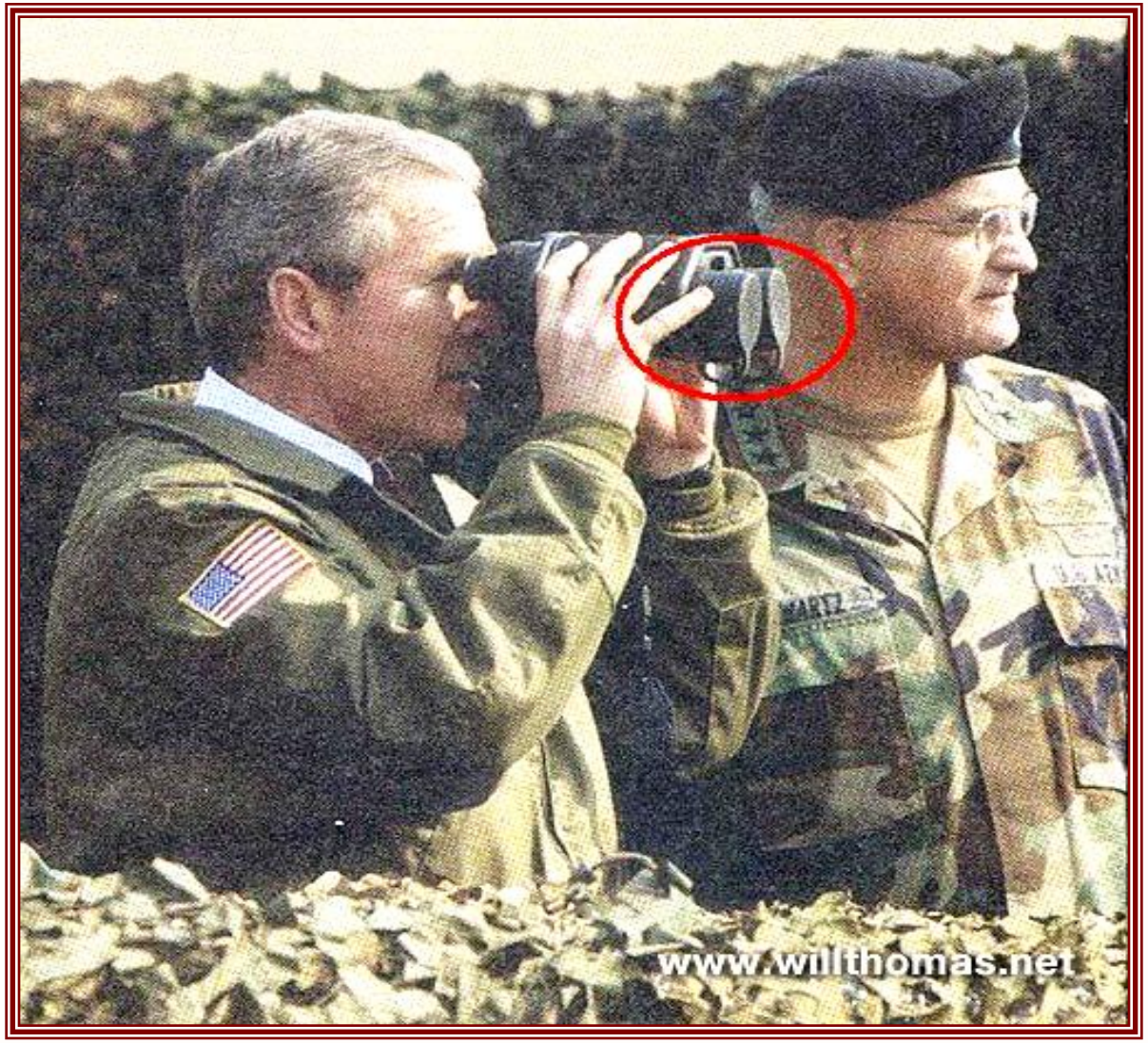
Baldwin, 2006

- “There is a need for a more proactive ethical approach to use of emerging technology.” Baldwin, 2006

“Rather than responding to developments we would, perhaps, be better to work out and agree in advance what sort of values and ethical considerations we want technology to adhere to.” Baldwin, 2006

- We need to proactively develop more “Positive” uses of technology that fit our ethical vision, build and sustain relationships and enable well-being and personhood.

It’s not the technology



It’s what you do with it that counts

Assistive technology for people with dementia…

- Needs to be based on an individual assessment of the person's capabilities, priorities and wishes – not just risk or need
- Needs to be based on an assessment of the way the person makes use of activity – that is the role such activities play in their lives, their meanings and routines
- Should aim to increase the fit between the person and environment – not to decrease it.
  - That is it should bring the world more fully within the person's grasp, not help make it more complicated or push it further away
  - be enabling and supportive, not restrictive
  - not exacerbate feelings of failure, powerlessness or infantilisation
  - enhance confidence, self-esteem and feelings of competence
  - not give frightening or confusing signals
- Should enable the person to maintain a balance of activities and social roles
- Should be meaningful to the individual; this means providing real choice, based on clear and collaborative assessment and consent processes, sensitive to people's culture and life histories

Assistive technology is one possible means to an end, not an end in itself

- Always consider human solutions and role/needs of person and carers
- **When technology is used it should be to enable the person, not disable them further**
  - promote participation and inclusion, meaningful activity and mobility
- **Don't overwhelm person with technology or changes**
  - Instead go at person's pace and build on what they do and know already when possible **– start simple**
- **Technology is not a quick fix**
  - only as good as the package of care, support and treatment that goes with it
- **Person and relationship centred assessment is key**
  - Consider ethical and legislative context and guidance
  - Positive risk taking
  - Use professional reasoning, reflective practice, critical thinking

References

- Astell, A. (2005). *Developing Technology for People with Dementia.* Psychiatric Times. November 2005: Vol 23 (13).
- Astell, A J; Bouranis, N; Hoey, J; Lindauer, A; Mihailidis, A; Nugent, C and Robillard, J M (2019) Technology and Dementia: The Future is Now
  Dementia and Geriatric Cognitive Disorders, Volume 47, Number 3, pp131–139
- Baldwin, C (2006) Reflections on ethics, dementia and technology. In *Assistive Technology in Dementia Care,* Woolham, J (ed). 2006. Hawker publications
- Brownsell, S, Hawley, MS. (2004) Automatic fall detectors and the fear of falling. *J Telemed Telecare,10:* 262-266
- Dewsbury, G and Linskell, J (2011) Smart home technology for safety and functional independence: The UK experience. *NeuroRehabilitation* 28 (2011) 249–260
- Evans N, Carey-Smith B, Orpwood R (2011) Using smart technology in an enabling way: a review of using technology to support daily life for a tenant with moderate dementia. *British Journal of Occupational Therapy* 74(5),249-253
- Gibson, G., Dickinson, C., Brittain, K. and Robinson, L. (2019) 'Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them', *Ageing and Society*, 39(11), pp. 2502–2519. doi:10.1017/S0144686X18000661.
- Marshall, M. (2003). *Not just because we can do it*. Journal of Dementia Care Nov/Dec 2003.
- Sommerville I and Dewsbury G (2007) Dependable Domestic Systems Design: A Socio-Technical Approach, *Interacting with Computers,* Springer, Volume 19, Number 4, July 2007, 438-456.
- Steils, N., Woolham, J., Fisk, M., Porteus, J. and Forsyth, K. (2021) 'Carers' involvement in telecare provision by local councils for older people in England: perspectives of council telecare managers and stakeholders', *Ageing and Society*, 41(2), pp. 456–475. doi:10.1017/S0144686X1900120X.
- Wey, S (2004). *One size does not fit all*. In *Perspectives on Rehabilitation and Dementia.* Marshall, M (ed). London, Jessica Kingsley
- Woolham, J (2006) *Assistive Technology in Dementia Care: Developing the role of technology in the care and rehabilitation of people with dementia current trends and perspectives.* Hawker Publications 2006.