Assistive Technology as a Means of Supporting People with Dementia: A Review

This paper reviews the current policy and practice in relation to Assistive Technology supporting people to live well with dementia, including different housing settings and rounding off with some good practice case studies which highlight the wide array of technology solutions available.

Included in this thorough review are:

- Definitions and a brief summary of different types of AT

- A review of policy initiatives, including legislation, which have attempted to encourage the greater use of AT

- Ethical considerations

- Current practice by major housing providers

- Good practice examples

- People with dementia's experience

- Further reading links

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July 2012

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1   Dementia Facts and Figures

Dementia is a progressive cognitive disorder, as a result of which, those affected gradually lose the ability to carry out normal, everyday tasks. This progression will vary from person to person and each will experience dementia in a different way.

In the UK today, approximately 800,000 people have the illness generically known as dementia and by 2021 it is estimated there will be over 1 million people with dementia. That figure is likely to double in 30 years' time. One in 3 over 65's will be diagnosed with dementia. Dealing with dementia currently costs the UK over £23 billion a year. *(Source: The Alzheimer's Society, June 2012)*

Approximately 60% of people with dementia live in their own homes, generally with a spouse or other family member as their carer. The remaining proportion of dementia sufferers are either resident in care homes or in long-stay hospital wards. (It is estimated that more than 30% of hospital beds in geriatric wards are occupied by those with dementia).

There are a number of different types of dementia, the most common being Alzheimer's disease, which results in a gradual decline in cognitive function. Vascular dementia results in cognitive decline, often following a minor stroke. Frontal lobe dementia affects mood which can lead to aggression and inappropriate behaviour. Dementia with Lewy bodies is characterised by hallucinations, and muscle tremors and stiffness. Other forms of dementia include Creutzfeldt-Jakob disease (CJD), Huntington's disease, alcohol-related brain damage, and HIV/AIDS related dementia.

Dementia is thought of as an older persons' disease, and as a result, support can quite often be geared up for the over 65s. This means that for younger persons with dementia (e.g. those with Down's syndrome) treatments and services may not be age appropriate.

Those with dementia can exhibit a range of symptoms, from mild to extreme, but they can include:

Memory Problems: loss of memory, particularly short-term; forgetting of names of close friends and family; inability to recall the names and operation/purpose of devices and objects; losing the thread of conversations/ TV programmes. Forgetting to eat, drink and take medication.

Wellbeing Related Problems: anxiety and even depression due to forgetfulness; confusion and disorientation in relation to the surrounding environment; anger and frustration.

Communication: Declining conversational abilities; repeating oneself; poorer written communication.

The above symptoms can lead to the person becoming isolated, excluded and lonely. 'Wandering' is also a recurrent theme.

Specific risks, especially for a person living alone include:

- Falls,
- Hypothermia,
- Inappropriate use of household appliances,
- Flood and fire,
- Ingestion of toxins,
- Failure to take medication or over-medication due to short term memory problems.

Regular social contact including family support, interaction with friends, having pastimes and hobbies all help deal to some degree with the above issues.

Professor Tom Kitwood appears to have coined the phrase 'Rementia'. A rough definition is of a person with dementia regaining some of their lost skills as the result of outside intervention, such as greater social involvement and encouragement of the person to interact with their environment. A cited example of this *Rementia* effect is reported in the research results of the 'Smart' Flat set up by the Bath Institute of Medical Engineering (BEMI) for one particular Housing 21 tenant in St. George, Bristol.

The resulting technology helped the client to regain some lost skills, particularly in the area of social interaction. Professor Roger Orpwood, project lead stated:

> *"The really smart thing about the wireless technology we have used in this flat is that we can take the elements that clients find particularly useful and install them in their own home. The whole installation is quite unique because it is designed to empower the resident rather than relying on outside help to deal with problems."*

2   Assistive Technology

There is no definitive or all-encompassing description of what Assistive Technology (AT) is, but this general definition could serve most cases:

> *"Any device which assists a person in retaining or improving their independence, safety, security and dignity."*

AT could therefore be considered as an umbrella term for a vast range of devices from simple grab-sticks, right up to complex lifestyle monitoring systems and even GPS safety-tracking. The most commonly recognised type of AT is Telecare, such as 'social' safety alarm systems usually activated by neck or wrist-worn pendants, but able to monitor a wide variety of activities and situations via additional sensors. Normally, any alert is picked up by a monitoring centre that contacts the resident, family, carers, mobile wardens or emergency services, depending on the seriousness of the situation.

Telecare equipment such as a pendant is sometimes viewed (not least by the user) as a 'badge of vulnerability.' The very concept of alerting creates a self-perception that the user is a 'problem'. Unfortunately, Telecare is often seen as the be all and end all of Assistive Technology, whereas AT can achieve much more, sometimes with quite simple equipment, without resorting to the use of 'high-tech' cutting edge devices.

Unfortunately, despite some excellent sources of information, there is little general awareness of what devices are available, and what benefits they can bring. This creates reluctance from potential beneficiaries and their advisers to consider them as a valid option to more traditional call systems.

While there are industry-led standards and codes of practice, it must be noted that currently there is no formal central guidance around what constitutes 'good' AT, no key indicators etc. This situation requires addressing as there is the risk that solutions will be sought which only partly achieve the required aims - or not at all - and the confidence in AT solutions is undermined.

Awareness of the products, devices and solutions available is still sketchy and variable around the UK. There is almost a 'postcode lottery' relating to the quality of AT solutions available to people with dementia due to the varying approaches taken around the country.

Taking the above into consideration, it is an unfortunate fact that AT in its many forms can fall very easily fall into disuse, despite its very real beneficial features. A review document produced by the Institute of Rehabilitation Research in The Netherlands (2003) showed that there can be a 'fall-off' of use of up to 75% for a variety of reasons. Short of replicating the full list of reasons for non-use, the main factors relate to:

- Poor assessment of client needs;
- Inappropriate choice of equipment;
- Lack of client support and instruction;
- Lack of carer / family support and instruction;
- Lack of continuous support for client and/or carer;
- Equipment not meeting clients and carers expectations and/or needs.

Telehealth also sits within the umbrella group of Assistive Technology and, in the simplest terms, it refers to remote monitoring of a person's vital signs. Readings are transmitted to an appropriately trained person who can interpret the health readings and make decisions about potential interventions in real time, without the patient needing to attend a clinic.

Telehealth is seen as a suitable option for managing a patient's long-term medical conditions such as COPD (Chronic Obstructive Pulmonary Disease) without the requirement of the patient occupying a hospital bed or making repeated visits to out-patients departments. As will be seen later in this review, a number of recent initiatives are focusing on the widespread use of telemedicine technologies.

3 Assistive Technology and Dementia

AT devices as already stated, cover a wide range of complexities and uses. Broadly, assistive technologies fall into two wider categories, and they are 'Active' Devices and 'Passive' Devices.

An active assistive device is one which requires the direct action of the user to make it work. Examples include remote control devices such as door motors, and even the pendant button of a social alarm.

A passive assistive device is one which operates without the intervention of the user (in fact, if the end user is a person with a cognitive impairment, they may not even be aware of the equipments existence). A passive device will generally operate automatically in response to some external event. Examples include a Fall Detector, a Flood Sensor and a Bed Occupancy Sensor.

For the most part, assistive technologies utilised by those persons with dementia fall into the category of passive devices and AT devices and they typically include:

3.1 Reminders/Prompts

These are devices which help people whilst their dementia is still at the mild to moderate stage, and are having short term memory problems.

These are usually configured to operate at particular times and provide some sort of audible alarm (a 'beep' or a recorded message). These may be set to remind a person to take medication, that it is time for an appointment etc. Prompts may be set to respond to movement and give an appropriate message e.g. "Don't forget to lock the door", "Don't forget your keys" etc.

In extreme cases, where a person's cognitive ability is particularly impaired, the prompts may be set to stop a person doing something which may be harmful e.g. "Don't go out" "Don't switch the cooker on."

3.2 Safety Devices

Short-term memory problems may lead to potentially dangerous or harmful situations arising. Equipment can be used to minimise the risks of these events occurring.

Examples of equipment include: Automated shut-off devices for cooking appliances (in the event of a fire alarm being triggered) or water isolation devices (in the event of a tap being left running.)

Many devices can be linked to the telecare 'community' alarm unit mentioned above, which can be used to summon assistance in the event of an alarm being raised. This may include a fire or flood alert, a notification of a fall, an alert when they fail to get out of bed in the morning, or perhaps sending an alarm when a person leaves the house at an unusual time of the day/night.

The latest GPS technology has enabled users to wear traceable devices to ensure that 'wandering', and the risks it presents, is controlled.

3.3 Reminiscence/Entertainment

A person with dementia retains a good grasp of past events, at least during the early stages of their condition, even if their short-term memory is badly affected. Reminiscence tools can be used to help communicate with a person with dementia and to help stimulate them. This stimulation can come from something as simple as looking through a photograph album, but more sophisticated options are available.

These can include the use of audio-visual equipment either on a computer or a television, and to improve accessibility are often used in conjunction with a touch-sensitive screen rather than a keyboard or mouse.

The Alzheimer's Society neatly summarises the benefits that AT can bring:-

"Assistive Technology can:

- promote independence and autonomy, both for the person with dementia and those around them

- help manage potential risks in and around the home

- reduce early entry into care homes and hospitals

- facilitate memory and recall

- reduce the stress on carers, improving their quality of life, and that of the person with dementia"

(Source: Alzheimer's Society Factsheet)

4   The Ethics of Assistive Technology

It is reasonable to say that as long as technology has been used to support those with dementia, there have been discussions on the ethicacy of its use. A recent review paper by Beatrice Godwin (2012) does indicate that very few of the ethical concerns by professionals and carers have been assuaged and that they still create a barrier to the uptake of AT. It also indicates that whilst the general public readily embraces electronic 'gadgets', professionals are more reticent about their use. (That is, in a professional capacity, and not necessarily in their own personal lives!)

Concerns about the over-use of prescription drugs as a 'chemical cosh' for those with dementia still prevails (and rightly so). Using a similar descriptive device, the inappropriate application of AT could be seen as a 'technological strait-jacket'.

Numerous papers have been written about the issue of the ethics of the application of AT. One which stands the test of time is a 'guidebook' produced through the TED ('Technology, Ethics and Dementia') European Research Project (1999). It provided a tool for practitioners in dementia care to assess the benefits (and drawbacks) of AT use when supporting a client.

Drawn directly from the TED publication is one stage of the assessment process: A decision 'tree'.

It states that any question for which the answer is 'YES', AT can be considered, for any where the answer is 'NO', AT should not be used:
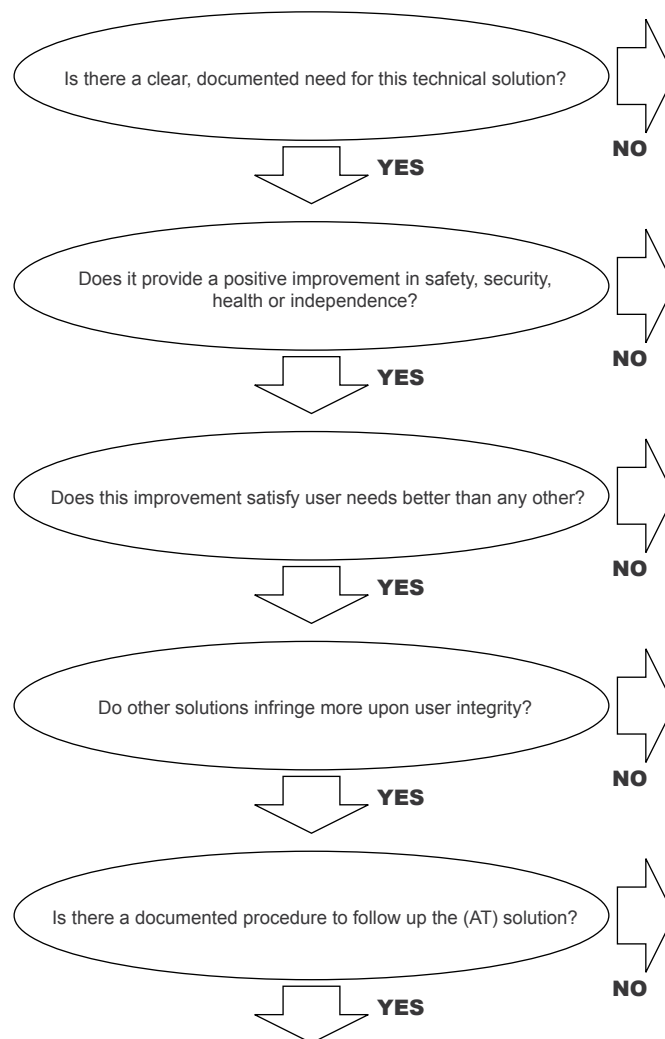
The Alzheimer's Society has outlined similar considerations as regards the appropriate use of AT.

These are:

- The risk of social exclusion. For example, the fear that assistive technology may be used to cut back services and reduce human contact;

- The potential threat to independence. For example, some devices may be used to do things a person is still able to do for themselves, which may increase dependency and exacerbate their problems;

- That they make people's lives and living environment more complicated or may make technical requirements of people which are beyond their abilities;

- That they may help foster a one-sided focus on a person's problems and not on promoting their existing strengths, thereby damaging the person's self esteem;

- The issue of consent. For example, technological solutions might be employed, especially those that may restrict freedom of privacy, without fully involving or obtaining consent of the person with dementia;

- Data protection issues around the use of computer technologies that rely on sharing information and ensuring such information is not misused or allowed to fall into the wrong hands;

- Stigma. Some people with dementia may feel stigmatised by assistive technology.

(Source: The Alzheimer's Society, Assistive Technology Position Paper, May 2011)

It is always important with the implementation of AT to include the considerations and wishes of the end user. Wherever possible, the direct involvement of the end user should be sought, in conjunction with any familial members or informal carers.

An individualised, 'person-centred' approach should be used in any evaluation process, and from that, should emerge any of the relevant ethical issues, which help highlight any concerns of the involved parties. A classic example is the ethics of using bed, chair or door sensors to determine the movements of a 'wanderer', along with a GPS location tag - versus the perhaps far more ethically dubious option of effectively locking them in their own home.

One of the key questions as regards the use of AT with a person with dementia is who is the ultimate beneficiary of the use of the technology? There is no doubt that a full-time family carer will benefit from alarms, alerts and location devices, as they contribute to both the carer and the cared for being able to live a more normal life, as well as giving the carer the chance for some respite with peace of mind.

Inevitably, utilising AT can also be perceived as a means of reducing levels of care and care costs. By doing so, inevitably there is a possibility of the reduction of human interaction between the person being supported and their carer(s). It should of course be considered that the use of AT can improve both the 'quality time' a formal or informal carer can spend with a person and, by supporting not just the user but the carer also, make their time together more mutually rewarding.

What is the true alternative to the use of Assistive Technology for a person with dementia? The first few paragraphs of this paper outlined the increasing proportions of older persons within our society, of whom, it is inevitable (barring a major medical breakthrough) large numbers will succumb to Alzheimer's.

5 Assistive Technology Initiatives & Policy

In 2004, an Audit Commission report said that telecare and telehealth could support independent living for older people by:

- Reducing hospital stays by supporting earlier discharge;

- Virtual visiting e.g. monitoring the safety of persons with dementia who live alone;

- The use of reminder systems e.g. medication;

- The use of home security and social alarm systems – for example, smoke and heat detectors, alarm systems and crime surveillance, as well as monitors that pick up any unexpected changes to an older person's routine.

In July 2005, the Department of Health published *'Building Telecare in England'* where it emphasised how: *'Telecare offers the promise of enabling thousands of older people to live independently, in control and with dignity for longer'*. This report was timed to coincide with the launch of the £80 million *Preventive Technology Grant*.

5.1 Preventative Technology Grant/Telecare Development Programme

The announcement of the *Preventative Technology Grant* (PTG) was the first real suggestion that AT may finally be considered as a mainstream care option. This amounted to an £80 Million government investment, spread over 2 years with the funding being directly provided to English Local Authorities. The PTG undertaking was due to commence in April 2006. The grant was allocated proportionally based on the support needs in a specific authority area for vulnerable persons. The intention with the PTG funding was to invest in telecare services to allow a person to be supported at home and avoid unnecessary admissions to nursing home care or hospital.

A similar initiative was launched in Scotland in the same year. The *Telecare Development Programme* released a budget of more than £16 Million over 4 years, with broadly the same aims and goals for Scotland as those expressed for PTG in England.

A concern in some spheres was about the allocation of the funds to these initiatives, as the budget source was not 'ring-fenced'. This meant that any LA could effectively choose to spend their grant allocation on bolstering up any existing social care provision without developing the intended enhanced telecare services, or indeed use the money to support other (non-care) services.

It has been intimated from sources that the combined marketing influence of some of the equipment providers, and the pressure on departments to spend their budget

allocations promptly (combined, perhaps, with a lack of technical confidence), lead to rash bulk purchasing decisions. It would come as no surprise therefore, if there were unused stocks of AT equipment gathering dust and slowly going 'out of date', sourced purely on the pressure to spend PTG/TDP budgets.

Current estimates (2010 figures) state that over 1.6 million people in England have some sort of social alarm monitoring equipment of which an unspecified proportion will include telecare devices. At present, users of telehealth devices probably number no more than 7,000. The general outcomes of how PTG funding had helped increase the use of telecare and telehealth equipment must have been considered reasonably favourable, as the next development towards mainstreaming the technologies (*'Whole Systems Demonstrator'*) was announced in May 2008.

Unfortunately there is no hard data as to what proportion of the PTG budget went to support the needs of those with dementia. A quote from a paper issued by the Alzheimer's Society (May 2011) perhaps implies that the funding was used for 'quick wins' of supplying basic social alarm packages rather than tailored solutions for those with dementia:

> *"...only a small proportion of activity was channeled into dementia".*

This is rather disappointing, as it would appear from a stakeholder survey conducted in 2006, of those who responded, their intended target client groups for PTG expenditure ranked people with dementia as only second to older persons generally.
(Ref: INDEPENDENT Project, February 2007)

5.2 Whole System Demonstrator

The Whole System Demonstrator (WSD) commenced in May 2008, and was to be a three-year £30 Million research project. It published its outline findings in December 2011.

A Department of Health lead initiative, it was the largest trial of telehealth and telecare in the world. It involved the cooperation of over 3,000 patients and over 170 GP practices across Cornwall, Kent and Newham. The main disclosures were that the use of telehealth and telecare equipment and support services in the trial areas indicate a 45% reduction in mortality rates, a 20% reduction in emergency hospital admissions and a 15% reduction in attendances to accident and emergency departments.

The finalised first stage findings of the WSD have just been released (June 2012) which refer specifically to the clinical benefits of the trial. It is intended that a further report will be issued in due course which will outline the impact of the use of Telecare/Telehealth on costs of medical intervention.

The current findings can be found at: www.bmj.com/content/344/bmj.e3874

5.3 Living Well with Dementia

In 2009, the Government issued a 5-year strategy called 'Living Well with Dementia' and its key aims (in summary) are:

- Increased Awareness & Understanding – *addressing stigma and misapprehension, greater public debate*
- Early Diagnosis & Support – *of a better quality, better information and more support on diagnosis*
- Living Well – *Support networks, improved care, consider housing support & telecare's role, better care homes and improved end-of-life support*

Delivery of the strategy is to be through much-improved joint working between DH, NHS, Local authorities and other key stakeholders, with better-informed workforce.

5.4 Three Million Lives (3millionlives)

> *"The Department of Health (DH) believes that at least three million people with long term conditions and/or social care needs could benefit from the use of telehealth and telecare services. Implemented effectively as part of a whole system redesign of care, telehealth and telecare can alleviate pressure on long term NHS costs and improve people's quality of life through better self-care in the home setting."*

The *3millionlives* proposal is intended to carry forward the (yet to be fully announced) positive outcomes of the Whole System Demonstrator. This follows the original premise of the value of *Assistive Technology* in that it would allow a person to live more independently and in greater safety for longer, whilst also remaining in their own homes.

It has recently been announced that *3millionlives* will be taken forward by a concordat comprising the Department of Health as well as relevant trade associations, telecoms and telecare equipment manufacturers, and perhaps most crucially, representative groups of the recipients of these services.

A small initial seed fund donation of £10,000 has been requested from each organisation wishing to contribute to the initiative. At the present time *3millionlives* has 19 funders: 15 companies and four trade associations. Contributors to the seed fund so far include: 02, BT, Philips, Pfizer, Bosch and Tunstall Healthcare.

Perhaps the only cautious note to make is that a largely industry driven initiative may exclude the smaller representative groups from the decision making process as to how *3millionlives* develops.

For more on *3millionlives*, go to: www.3millionlives.co.uk

5.5 DALLAS

Announced by the Technology Strategy Board in Spring 2011, DALLAS (*'Delivering Assisted Living Lifestyles at Scale'*), with an allocated budget of £25 Million, had the intention to encourage bids for projects which would improve the health, well-being and quality of life for older and vulnerable persons in the UK.

Their criteria was that each project would be capable of reaching at least 10,000 persons per project, and that it was anticipated that up to 5 different projects would be supported.

It was finally announced on May 23rd 2012 that 4 consortia were successful in their DALLAS bids out of over 100 individual applicants, and that the combined output of the projects would provide support and assistance for nearly 170,000 older people across the UK.

No specific details have been made widely available at this time, but from the outline project descriptions, it would appear that at least 2 of the 4 projects will be making use of telecare and telehealth technologies at a scale never so far seen in the UK or in any other European country. It is suggested that by Summer 2015 the initiative will have returned some positive results, but no clear deadlines for specific goals have as yet been set.

As DALLAS is at such an early stage of its progression, as with *3millionlives*, it is impossible to say how much the initiative will impact on those with dementia. It is however hoped that between DALLAS and *3millionlives*, dementia sufferers will see a greater degree of support than PTG appears to have delivered.

For more on DALLAS, go to:
https://connect.innovateuk.org/web/dallas

5.6 Design Council Challenge – 'Living Well with Dementia' Technology Innovation Challenge

In conjunction with the Department of Health, the Design Council has created a challenge for innovators to look at positive options for addressing the rising costs associated with dementia and an ageing population.

The challenge was announced in August 2011, with the intention that 5 selected innovators would share a budget of £360,000.

Commenting on the project, Care Services Minister, Paul Burstow said:

"Dementia is one of the biggest challenges we face as the population ages. It currently affects 750,000 people in the UK and that number is set to double over the next thirty years.

"To make sure we continue to improve health outcomes and manage the growing costs associated with this, we need to think smart and do things differently."

This gauntlet was picked up by a number of groups and organisations, and the submissions were judged by an advisory board consisting of experts in dementia, health and social care, business and design, and chaired by Baroness Sally Greengross (Chief Executive of International Longevity Centre). The initiatives which have gained support comprise:

- 'Trading Times' – An online service linking informal carers for those with dementia with local businesses requiring casual employees. This means that those who would otherwise not be able to work and earn money due to their caring commitments can remain in employment.

- 'Ode' - An automated fragrance-release system. It releases 3 different food smells throughout the day to stimulate appetite and encourage regular eating patterns for persons with dementia. The timings and nature of the smells can be varied to avoid the recipient becoming immune to the positive effects of the odours.

- 'Grouple' – An online social support network to allow the carers of those with dementia to share the experiences and responsibilities of their roles. It also allows multiple carers for the same person to log events and experiences with the person in their care, thus benefiting from each others observations.

- 'Dementia Dog' – As well as providing companionship, dogs will be specially trained to support daily patterns such as waking, sleeping and eating. Audible prompts will allow the dogs to help with reminders relating to medication, hydration and toileting.

- 'Buddi-Band' – A development based on the existing Buddi GPS location system. The Buddi-Band will be a less bulky version of the Buddi with the same location facilities incorporated on a lightweight wristband. As well as operating whilst the user is on the move, the Buddi-Band can be used as an emergency call system in the home, with a combined loudspeaker unit and charging 'dock'.

More details about these projects can be found at:
www.designcouncil.org.uk/dementia

5.7 'National Challenge on Dementia'

Prime Minister David Cameron has made a number of announcements over the past couple of months as regards enhancing current budget expenditure into dementia care and research. This has included a pledge in March 2012 to more than double the current annual research funding to £66 million by 2015 as well as a national screening programme to check for early signs of dementia in people between the ages of 40 and 74.

Also, on May 22nd 2012 it was announced that a further £30 million would be made available to methods of

managing behavioural issues with dementia sufferers. The intention being to reduce the incidence of use of potentially harmful anti-psychotic drugs which are known to result in 1,800 premature deaths every year due to stroke and other medical complications.

Paul Burstow MP, Care Services Minister stated:

"Far too many people with dementia are robbed of part of their lives because they are needlessly given anti-psychotics… By taking people off these drugs, we're turning the lights back on for thousands so they can live a more meaningful life".

Care professionals have discovered that there are alternatives to drugs to help calm the difficult behaviour of those with dementia.

In one instance, a resident who had been a Prison Officer had an obsession with keys and became easily agitated. The solution was to install a block of wood fitted with 5 locks (and keys) inside her room. This reduced her anxieties about security.

In another case, installing seats and a 'Bus Stop' in an internal corridor helped stop two elderly ladies from leaving their scheme every afternoon. They wished to go out as they recalled an earlier time in their lives when they would go to collect their children from school.

The above two cases are classic examples of using *simple* 'low-tech' assistive devices as a means of supporting people with dementia. *(Having said that, it has been pointed out by a contributor to this review that in the instance of the ladies at the 'Bus Stop', the more appropriate course of action may have been for staff to actually take the ladies out on an accompanied walk instead of utilising the pretence of a functional bus stop.)*

5.8 Personalisation of Care / Self Directed Support

Supporting People (revenue) budgets are being replaced with the new 'Personalisation' agenda in England and Wales ('Self Directed Support' in Scotland). This means that a person eligible for receiving care support packages will take greater control of the type of personal care support they receive, what form that will take and who they obtain that care from.

Not withstanding the issue around an individual with dementia's personal ability to oversee how that care is managed, it means they will be assessed for the value of the care package they require, and as a result, will be able to choose to spend their care budget allocation in an appropriate manner, using a care team of their choice.

Could this also mean that if the person so chooses, they can opt for a lesser level of personal ('human') care and replace it with *Assistive Technology?* It opens up an interesting debate that a customer may wish to make use of technology, paid for through their personal budget to maintain (or enhance) their independence and thus reduce their reliance on formal carers, whilst personal independence is either maintained or possibly even improved.

Despite what is developing amongst the other telecare and telehealth initiatives *already described*, the issue of implementing technology, as part of a self-managed care package, does not seem to be appearing on the radar. Is it possible that the use of assistive technologies could become a valid option as part of a personal care package?

5.9 Social Care White Paper 2012

The present government made a commitment to review the current system of funding social care – and the potentially disastrous burden on individuals - when it came to power two years ago, and commissioned a wide-ranging review soon after.

In 2011 the Dilnott Commission on Funding Care and Support acknowledged that the "current funding system is in urgent need of reform - that it is hard to understand, often unfair and unsustainable"

That report's recommendations set out how Government could dramatically improve the system including:

- Individuals' lifetime contributions towards their social care costs be capped. After the cap is reached, individuals would be eligible for full state support. The cap was suggested to be around £35,000;

- The means-tested threshold, above which people are liable for their full care costs, should be increased from £23,250 to £100,000;

- National eligibility criteria and portable assessments should be introduced to ensure greater consistency;

- All those who enter adulthood with a care and support need should be eligible for free state support immediately rather than being subjected to a means test.

Also in 2011, the Law Commission recommended the streamlining and modernisation of the legislation, creating a coherent social care system.

The commission recommended:

- putting an individual's well-being at the heart of decisions;

- giving carers new legal rights to services;

- placing duties on councils and the NHS to work together;

- building a single, streamlined assessment and eligibility framework;

- giving adult safeguarding boards a statutory footing.

The long awaited Social Care White Paper, '*Caring for Our future: Reforming Care and Support*', has responded to these calls by setting out broad in-principle agreement with the Dilnot and Law Commission recommendations,

disappointingly holding back, for the time being, how they intend to fund them. There was, however, news of £200m capital allocation over a 5 year period, to fund up to 6,000 new units of specialised housing for older and disabled people.

The Housing LIN responded to the announcement on 12 June:

"Despite hesitating on amber while the implications of how the recommendations of Andrew Dilnot's Commission should be implemented, the White Paper signals the government's commitment to building a platform for the future direction of adult social care. In particular, it sets an agenda that seeks to clarify roles and responsibilities between the state and individuals in the context of enhancing further choice in the market place, offering greater control to individuals, creating stronger communities, facilitating more co-production, and making best use of all resources."

The full response from the Housing LIN can be found at: www.housinglin.org.uk/News/HousingNewsItem/?cid=8547

Finally, the Housing LIN is a member of the Prime Minister's 'Dementia Champions' Group and will advocate the importance of housing and telecare/health solutions to support people with dementia to live well at home.

For more about housing and dementia, go to: www.housinglin.org.uk

6   Examples of Recent Dementia Care Initiatives Using AT

As long as AT has been available to practitioners, the more forward thinking and adventurous of them have explored the potential use of that technology to support customers with specific support needs, including dementia.

A better understanding of the care requirements of dementia sufferers, combined with advances in assistive technologies has created numerous practical examples of AT use. These experiences are worth sharing:

6.1   Norfolk County Council

As far back as 2006, Norfolk County Council was keen to mainstream AT into its social care services. Their AT Services Manager states that initially they attempted to equip all social care assessors with AT knowledge through training, and making AT a part of the assessment process, but due to the assessor's infrequent contact with AT, this knowledge dissipated quickly.

Instead, Norfolk placed highly trained AT Practitioners amongst local assessment teams to be on hand when the expertise was required for advice, installation, technical backup and to promote the benefits of AT whenever possible. This has worked much better and has ensured mainstreaming of AT has occurred.

Norfolk appear to have a very wide view on what constitutes AT and distribute a wide array of telecare and standalone equipment, from 'day and night' calendars, medication prompts, telephone prompting (person to person rather than automated) and 'Buddi' GPS trackers: www.norfolk.gov.uk/Adult_social_care/Support_at_home/Assistive_technology/index.htm

Norfolk have even produced a helpful video on the topic: www.youtube.com/watch?v=ZobJzaPPw-U&lr=1&uid=L_svqSfy2uq4d5ZoxJvnzg

The AT team have also been instrumental in the utilisation of telehealth monitoring in the county, now managed by their local Health colleagues.

6.2   Lambeth Council

The council's AT lead has acknowledged the dilemma of whether to go down the specialist officer route or train all practitioners in AT. She stated:

"I think a hybrid solution may be the answer, depending on a variety of factors such as location, history, and so on.

"In Lambeth, we have found that dementia is one of the most relevant areas in connection with the use of Assistive Technology and Telecare.

"In an evaluation which we completed jointly with the former DH's CSED team dementia was shown to be one of the areas where AT/telecare is most effective with significant links to cost-reductions.

"We have found that the targeting of individuals who would be most suited for support through AT/telecare using good assessment processes was a key-factor for success, along with a multi-disciplinary approach, working closely with carers and closely maintaining / monitoring the systems and associated services to ensure contingencies.

"We have been solely operating within the framework of FACS with people who have critical and substantial social care needs, working very closely with care managers who will integrate AT/telecare services into careplans."

Furthermore, the Lambeth's AT lead believes the assistive equipment is only one part of a big jigsaw and should not be considered in isolation.

"The individual's personal circumstances will affect the impact of AT. Some take to it well, others don't. What I am clear on is that joint working, better planning and a multi-disciplinary approach should be our focus not individual pieces of kit."

However, she did highlight some hurdles which did relate to AT devices:

"Dominant suppliers, lack of integration and interoperability are not helpful."

www.scie.org.uk/publications/guides/guide33/files/guide33.pdf

www.csed.dh.gov.uk/AT/

6.3 Willow Housing and Care

Beechwood Court Extra-Care scheme appears to be built specifically with dementia clients in mind, creating an environment which incorporates very helpful features.

It opened in January 2012, and as their Sheltered Housing Team Leader, explains:

"We have included a higher level of security at the scheme than previously; we also have flood detectors in kitchens and bathrooms and smoke detectors linked to the community alarm. We have 'memory boards' on individual doors and are alerted if a resident leaves their flat. Flooring is differently coloured in different areas to aid wayfinding. The flats are able to have additional assistive technology fitted to meet individual requirements.

"There is an activities coordinator who works across 4 schemes, to work with residents, one-to-one, with activities which help them reminisce, for example."

6.4 Manor Gardens, Bolton

Places for People developed this extra-care scheme in 2009, with AT in mind from inception. As a result, every flat has fused spurs in appropriate locations to enable rapid installation of automatic door and window openers and motorised curtain tracks. (In addition to a basic 'AT-ready' wiring infrastructure, the scheme has strengthened walls/ceilings in the bathrooms to accommodate grab rails and tracking hoists, as and when the resident requires them.)

As well as the modern call alarm system with full telecare/telehealth capabilities, the scheme has Digital Signage and Interactive Noticeboards, touch-screen video ('Skype') facilities and an IT Suite plus full on-site Broadband access allowing wired and wireless internet connections for each resident.

The Manager stated that:

"By building in AT from scratch, we have avoided unsightly and disruptive retro-fitting after the resident has moved in. Those who don't need any assistive equipment haven't been left with grab rails or automated mechanisms, but they can be fitted easily if they require them at a later stage. This was particularly appropriate because a proportion of the flats were offered for sale on the open market and our sales and marketing colleagues wanted a 'clean' look."

Many of the residents at Manor Gardens have dementia of varying degrees from mild to moderate, and the team have been using initiatives which are not considered traditional AT.

"We've used 'talking books' which our in-house AT team created, to help residents reminisce with photos and music, or to act as a reminder device.

"We also found holding 'YouTube' sessions in our IT suite was invaluable for reminiscence purposes as there are so many clips online from their earlier life.

Also, our video box (which utilises Skype), helped connect people with loved ones from around the world and this was a great source of comfort and pleasure."

6.5 Connect Care – Newcastle Social Services

Video conferencing was a core driver for another innovative initiative implemented in the North-East, known as 'Connect for Care', based in Newcastle.

The project was funded by Newcastle Social Services with the technical support of the local consultant old-age psychiatrist.

Essentially they harnessed the power of video telephony to help those with dementia of age 75 upwards to connect with relatives, carers and friends. The consultant confirmed that:

"There were a number of drivers including the problems of social isolation, difficulty in traveling, social stimulation and access to healthcare staff."

The basic hardware was a touch-screen PC with a simplified software menu to demystify the technology and to encourage use.

There were attempts to integrate telecare and telemedicine solutions with the system but because telecare is based on standard telephone line connections and successful video conferencing requires broadband, this was never fully realised.

Other challenges included users switching off the system out of habit to save energy and the requirement for an IT support team to overcome technical issues. This project has now ended due to lack of funding.

Users found it helped them deal with feelings of isolation, family members were able to assess their well-being using visual clues as well as spoken words and carers felt the system aided them in their daily role and reduced their stress levels.

Despite the fact that the project has now ended, some users continue to use the system and it is interesting to note that video telephony appears to continue to be considered a key element of AT/ telehealth. Significantly, in the words of the consultant:

"The users really shattered some prejudices we held about older people and their reluctance to use technology!"

www.connectforcare.com

6.6 Hull Telecare

As stated at the beginning of this report, AT, considered in its widest sense, can encompass virtually any device whether it be low or high-tech. Some providers have put into practice this approach and have shown great innovation and flexibility.

The Hull Telecare Coordinator wanted to share his experiences of how he and his colleagues have tried to step outside the AT norm:

"We have used Just Checking for assessment purposes and in terms of telehealth, we have equipment in multi-occupancy dwellings where people with dementia can utilise the health observation part of the system, using the equipment with the assistance of a carer. We even ensured our residential units for people with dementia were all ready for the digital TV switch over long before it happened."

He contends that it's often the simple and cheapest devices that are the real 'life changers.'

"Through an initiative called 'saEAT', we supplied a whole variety of low cost (<£30) equipment that provided assistance to carers and people with dementia including: water level indicators, memo minders, PIR LED night lights, 'driveway' alerts (a security device that was used as a property exit sensor at very low cost, sourced from the USA)."

This last device is an example of how AT can be obtained very cheaply and be utilised effectively.

"The usual routes cost a lot of money because as soon as they become a 'health' or a 'care' device, companies add a couple of zeros on to the cost because they know it has gone from a want to a need – the more socially aware companies provide a lower level solution which actually suits the situation better and the client themselves can afford to get it."

There is a procedural hurdle to maximising the effect of these simple solutions, says the coordinator:

"In Social Services our criterion for providing services is Substantial & Critical which makes the justification for provision of low level equipment a difficult one to swing. It is 'true' prevention, but for the majority of clients we get to assess they are further down the road in their conditions – Catch 22 of 'if only we could have got in 6 months ago'; but then 6 months ago they would not have met the criteria to get services from us."

Moreover, he would like to see a High Street presence for AT devices- a *"not for profit shop with a social conscience"* as he calls it. *"A shop front similar to those that the mobile technology companies have where you have a gadget/product area and a comfy area to assess, plan and look at implementation of both kit and services."*

"I believe this would not only increase the public's awareness of these technologies but also act as a teaching / training centre for staff across health, social, housing, education, leisure services."

6.7 University of Edinburgh – Safe Walking with GPS

(The Use of GPS in Wandering People with Dementia: Feasability Study)

In September 2011, the University of Edinburgh began an assessment of the value of using Global Positioning Satellite (GPS) technology as a means of supporting and safeguarding people with dementia.

They wished to look at genuine alternatives to restricting the movements of those with dementia, such as locking doors, making a door difficult to open, or using floor patterns / colour schemes which would discourage crossing a threshold. Hence the exploration of GPS technologies.

The project aims were to:

• Determine the acceptability of the technology to service users, carers and health and social care staff.

• Determine the feasibility of cost and outcome measures for an economic evaluation.

• Test feasibility of recruitment into a randomised controlled trial.

• Estimate variability of measures of stress on carers and time to admission to long-term care.

In conjunction with NHS Lothian PCT and Social Services in Edinburgh, East Lothian and Fife potential users of the GPS technology were identified. Originally the intention was to recruit 20-25 customers, but at this time there are 12 participants in the trial.

The participants are currently using two forms of GPS location devices. They are the Everon 'Vega' and the Skyguard 'GEMshield'.

Unfortunately as the initiative has yet to reach its conclusion, we are unable to report on how effective the trials have been.

Very early indications with two female clients in Edinburgh would seem to imply a good level of success and satisfaction. Refer to the attached media links for more details.

http://news.stv.tv/scotland/east-central/282364-dementia-patients-tagged-with-gps-trackers/

http://local.stv.tv/edinburgh/28112-gps-equipment-to-be-rolled-out-to-help-dementia-patients-in-edinburgh/

www.scotsman.com/edinburgh-evening-news/health/dementia_care_is_given_gps_boost_1_1985730

www.theedinburghreporter.co.uk/2011/11/council-trying-out-safe-walking-service/

7   Finally.... A Users Perspective

At a recent event in the Scottish Borders ('Dementia 2012 – Think About It') there was an opportunity to hear first hand the experiences of those with a diagnosis of dementia. One user, an ex-police officer, spoke of his experiences of a diagnosis of vascular dementia approximately 2 years ago. He is also Vice Chair of his local Neighbourhood Watch, and is now an active committee member of the Scottish Dementia Working Group.

Another user, a nurse by profession, was a manager of a chiropractic clinic before her diagnosis of Alzheimer's over 5 years ago. She spoke passionately about her experiences and appears to be a well-seasoned guest speaker. She is also the Chair of the Scottish Dementia Working Group.

It became clear from her presentation at the event that she had personal experience of the use of assistive technology, so via email she was asked her opinions of its value in her daily life. Her powerful and stirring response has been reproduced here verbatim. It was felt inappropriate to correct any of her spellings or grammar as retaining the metre of her own email seems to better convey the message:

"I am the current chairperson of the SDWG and have a diagnossis of Alzheimer's for 6 years now

*Yes for over 2 years now I use a sensor monitor with my own voice recorded with a message that reminds me
to lock my door*

I love this a funny story it works so well now that my daughter was viviting and parking her car as normal I responded to my prompt and she had to phone me to reming me that she was outside I had locked the door as instructed consequently locking her our

*i also have the call monitor that I can press the button and get help this is great as once I was unable to use the
phone or get aid when I was poorly*

the fire brigate has also installed a smoke detector that goes off in the fire station allerting a immeadiate response

So I hope this is helpful if you need any questions answered just e mail me and I will try and respond

I cannot think of any downside to having this assisted technology my locality officer helps me and reminds me how to use them on a regular basis."

Hugs and Rainbows

Appendices

A   Case Studies

A1   Barchester Homes, 'Wood Green'

Issue	A new resident to the scheme with dementia was on a high level of anti-psychotic drugs. Regardless of this, he was extremely active and always on the move. He would rush around the scheme and event attempted to eat his meals whilst on the move.
AT Solution	Using the 'MyAmego' lifestyle monitoring equipment installed in the dwelling, this gentleman's activity profile was looked at by the scheme manager.
Outcomes	In conjunction with his GP, his dosages of anti-psychotic drugs were reduced until this medication was terminated altogether. The data collected about his movements using the lifestyle monitoring equipment helped staff create an accurate assessment profile of his activities. As a result of being able to act on this collected information, staff where able to better meet his needs, and address his habits and lifestyle.

Contact: Neil Bryant
MyAmego
www.myamego.com

A2   Warwickshire County Council

Case Study 1

Issue	The clients were two sisters who previously lived in separate sheltered housing schemes. Carers would take one sister (who had dementia) to other sister's flat every day to spend the day together and then return her home afterwards. They both moved into an Extra Care Housing development and had flats next door to each other. Shortly after the move the other sister was diagnosed with dementia.
AT Solution	Assistive technology was used to help with medication. A *Pivotell* medication dispenser was supplied. A door sensor was fitted, as one sister tended to wander at night. As part of the existing internal call system, the sisters were provided with 'pendant' call buttons fitted to wrist straps. Grab rails and associated equipment were also fitted in the bathroom to allow both sisters to shower without assistance. Care staff also supported the sisters and their family to improve their orientation within the scheme, and in maintaining a daily routine.
Outcomes	Both sisters have now settled well into their new environment.

Case Study 2

Issue	A gentleman with advanced dementia moved to an extra care scheme with his wife. His wife as his principal carer was under tremendous stress and was unsure how much longer she could cope. Their previous home environment was limiting and the gentleman would frequently get up at night. Unfortunately his mobility was poor and he would fall regularly, which meant frequent calls to the paramedics.
AT Solution	initially the gentleman's wife attached a cord from the call system to her wrist and her husband's wrist, so if he got up during the night it tugged her wrist to wake her up. Unfortunately the gentleman kept taking the cord off. A pressure mat was located next to the husbands bed, which connected to a 'stand-alone' portable alarm which his wife either had next to her side of the bed or with her if she was in another room.
Outcomes	This worked very effectively and the husband has had no further falls.

Contact: Sarah Coyle
Senior Occupational Therapist
sarahcoyle@warwickshire.gov.uk

A3   Norfolk County Council

Issue	Mr A in his 70's, lived in rural North Norfolk and had early onset-moderate dementia. He was very physically able, and had recently lost his wife who was his main care and support.
	His daughter had moved in with him to support him but she was finding this a heavy strain on her children and family. Mr A liked to walk his dog at least twice a day, while his daughter was at work. In the summer he had been found by a member of the public at Norwich Airport, confused and trying to get a bus back to his home 24 miles away. The event unfolded that he had walked the 24 miles (or more) with his dog and both were found de-hydrated and disorientated. Mr A wanted to continue with his independence and walking his dog as he felt this was his only remaining reason for life. His daughter obviously was concerned and wanted this to cease but didn't know how to proceed.
AT Solution	An assessment for a *'Buddi'* GPS device was completed by an AT Practitioner and the unit was programmed with a Geo-fence set-up. This enabled Mr A to continue with his independence and to go for walks. The Buddi would alert his daughter if Mr A was to go outside an agreed area within one mile of his home. It also enabled his daughter to check on her father from work or her own home when she was unable to drive there and visit.
Outcomes	Mr A's daughter was able to move back home and the Buddi support was successful for around 6-8 months. Unfortunately further deterioration of his condition eventually led to residential care.
	The Buddi saved residential care costs, informal care breakdown, potential police search costs and potential hospital admissions for 6-8 months.

Contact: Jonathan Langman
Assistive Technology Service Manager
jonathan.langman@norfolk.gov.uk

A4   Darlington Borough Council

Issue

Mrs B moved into an extra care environment as she was assessed as being unable to continue to manage independently within her own home due to deterioration of memory and cognitive capacity.

Following relocation to the scheme, Mrs B began to leave the scheme unassisted. It was thought that she was trying to return to her previous address. There were extreme concerns for her safety and well being as she was able to access public transport and was deemed to be vulnerable in these situations.

AT Solution

Mrs B had exit alerts fitted to the doors in her home, and was also supplied with a *Buddi* GPS locating device.

Outcomes

As a result of supplying and fitting the AT equipment, Mrs B has been able to remain safe within the extra care scheme, whilst allowing her free mobility within the building.

The use of the *Buddi* has allowed her own family to be made aware of her leaving the scheme, giving them support and reassurance. The equipment also ensures that Mrs B is rapidly located if she leaves the building, so has reduced the need for Police intervention, the need for an enhanced care package, and has reduced the likely need for hospital or care home admission.

Contact: Lynn Walker
Service Manager
lynn.walker@darlington.gov.uk

A5   Places for People

Issue

Mrs G moved in to Manor Gardens Extra Care Scheme with her sister. They both took a while to settle in to the new environment, particularly Mrs G. Soon after, sadly, the sister passed away affecting Mrs G very badly, who already displayed signs of mild Dementia.

Soon after, Mrs G kept getting locked out of her flat because she would leave her electronic door access fob in the apartment. This resulted in her getting lost and becoming confused within the scheme.

The social worker felt that the only logical next step was residential care, something which the family felt was going to traumatise Mrs G, after only just settling in to her new home and then losing her sister.

AT Solution

Our AT team were given an opportunity to rescue the situation and the family were willing to explore the use of assistive technology if it avoided residential care. They issued a fob 'wrist wallet' and a talking sensor in her room. As she left her flat, the sensor reminded her to take the fob with her in a voice she recognized and trusted (the scheme manager).

Outcomes

This solution avoided Mrs G from getting locked out of her flat. She has become so accustomed to the equipment that Mrs G now even tells the reminding device she has the fob before it speaks! This simple solution has transformed her confidence and general outlook. It also saved her having to leave a home she has just got used to, and one that she loves.

The solution cost less than £30.

Contact: Diane Emmison, Care Manager
Places for People Individual Support
diane.emmison@placesforpeople.co.uk

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C   Press Articles

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www.telegraph.co.uk/health/elderhealth/9283467/David-Cameron-to-announce-dementia-research-to-stop-chemical-cosh.html

"David Cameron promises a dementia funding boost" - 'The Guardian' 26th March 2012
www.guardian.co.uk/society/2012/mar/26/david-cameron-dementia-funding-boost

"Social Care White Paper is a wasted opportunity" - ' The Guardian' 13th July 2012
www.dh.gov.uk/health/2012/07/careandsupportwhitepaper

"Tackling Dementia" – Live Discussion – 'The Guardian' 16th April 2012
www.guardian.co.uk/healthcare-network/2012/apr/16/tackling-dementia-live-discussion

"What's happened to the Whole System Demonstrators?" - 'The Guardian' 10th April 2012
www.guardian.co.uk/healthcare-network/2012/apr/10/telecare-whole-system-demonstrators-wsd

D   Relevant Contacts / Links

AT Dementia   www.atdementia.org.uk
Design Council   www.designcouncil.org.uk/dementia
FAST   www.fastuk.org/home.php
HFT Virtual Smart House   www.hftsmarthouse.org.uk
Scottish Centre for Telehealth and Telecare   www.sctt.scot.nhs.uk
Technology Strategy Board (DALLAS)   https://connect.innovateuk.org/web/assisted-living-innovation-platform-alip
TEIS   www.teis.nhs.uk
Telecare Learning and Improvement Network   www.telecarelin.org.uk
Telecare Services Agency   www.telecare.org.uk
Wellbeing   www.welbeing.org.uk
Whole System Demonstrator Action Network   www.wsdactionnetwork.org.uk
3 Million Lives   www.3millionlives.co.uk

E   Acknowledgements

The views expressed in this paper are those of the author and do not necessarily represent those of the Housing Learning and Improvement Network.

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About the Housing LIN

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The Housing LIN welcomes contributions on a range of issues pertinent to housing with care for older and vulnerable adults. If there is a subject that you feel should be addressed, please contact us.

Published by

Housing Learning & Improvement Network
c/o EAC,
3rd Floor, 89 Albert Embankment
London SE1 7TP
Tel: 020 7820 8077
Email: info@housinglin.org.uk
Web: www.housinglin.org.uk