AKTIVE

The Role of Telecare in Older People's Daily Lives: experiences, practices and attitudes

Working Papers from the AKTIVE project 2011-2014

AKTIVE Working Paper 4

# Coping with Change: frail bodies and daily activities in later life

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Advancing Knowledge of Telecare for Independence and Vitality in later lifE

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*Research participants*

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# 1 Introduction

This paper explores responses to changes arising from bodily frailty observed among older people participating in the AKTIVE study and discussed with them during research visits. It identifies which daily activities were affected in older age and the strategies older people drew upon to cope. The paper also explores how telecare was combined with other support mechanisms to help older people maintain both practical and recreational daily activities. Throughout, there is discussion about limitations in how care support was sometimes provided, including how telecare was acquired and used by older people and / or those caring for or supporting them, and how far these problems might be overcome by more proactive implementation.

In exploring these issues, the paper complements and draws upon analyses presented in other AKTIVE working papers, which focus on: the study sample and the telecare in place (Yeandle, 2014a, Paper 1); older people's caring networks and how these are affected by telecare (Yeandle, 2014b, Paper 2); how telecare shapes and affects older people's social relations (Koivunen, 2014, Paper 3); issues of identity, stigma and choice (Hamblin, 2014a, Paper 5); and the role of telecare in how older people manage perceived risks to their independence, safety or wellbeing (Hamblin, 2014b, Paper 6; Buckle, 2014, Paper 7; both forthcoming May 2014).

The importance of everyday activities in the lives of older people has been well documented. A longitudinal study of older people by Menec (2003) showed that high levels of activity were related to enhanced happiness, better functioning in daily life, and reduced mortality. That study also showed that different activities resulted in different outcomes, with social and productive activities (such as meeting friends, travelling and gardening) positively related to happiness, physical and mental functioning and reduced mortality, whereas solitary activities (hobbies such as reading, sewing and painting) were related to psychological benefits, providing meaningful engagement in everyday life.

Research by Bowling (2008) showed that 'ageing actively' was greatly valued by older people; nearly half of the sample in their study emphasised the importance of physical health and functioning; a third stressed leisure and social activities; a fifth mental functioning; and a sixth social relationships and contacts. Bowling's work shows that for many older people, active ageing involves exercising the body and mind to maintain physical, mental and social functioning.

In another study, by Crombie et al (2003), almost all participants (over 400 older people living independently) believed that physical activity was beneficial and 80% believed they were active enough to stay healthy. Nevertheless, over a third participated in no leisure activities, while a fifth did so for only a few hours weekly. Crombie et al. report that lack of interest was the main deterrent to participating in regular activities; other factors included lack of access to transport, shortness of breath, bodily pain, dislike of going out alone or in the evenings, perceived lack of fitness and / or energy, doubts that exercise could lengthen life, not belonging to a social group, and doubts that meeting new people could be beneficial.

Some of the difficulties faced by older people who experience physical and / or mental problems are identified in Crombie et al's study, revealing how their ability to age actively is compromised, with reduced health and happiness a clear risk. For this group of people, other studies have also shown that regular activities are particularly important. For instance, for people with a susceptibility to falls, daily exercise may strengthen muscles, resulting in fewer falls (NICE, 2004). For people suffering dementias, social engagement and / or regular cognitive activities (such as practising hobbies) may delay the decline in functioning that characterises these conditions.[1] It is clear that having the capacity and opportunity to engage in regular everyday activities is an important way of maximising older people's physical and mental well-being.

The term 'frailty' commonly describes the gradual deterioration in bodily and social abilities which often occurs in older age, resulting in increasing levels of vulnerability.[2] In this paper, the term 'bodily frailty' is used to refer to the wide range of health problems reported by older people in the AKTIVE study, all of whom were included in it because they were either susceptible to falls and / or had memory problems or some type of dementia. Discussion in the paper draws on accounts from research visits and interviews with older people using telecare, diaries kept by them, observations made by researchers during visits to their homes, and various types of research contact with others involved in their care or support (Yeandle et al., 2014).

This paper focuses on older people's health conditions and the kinds of care support mechanisms they had in place, so it is important to identify some of their characteristics. In the sample of 60 research participants: 39 were female; 41 lived alone; 35 suffered a susceptibility to falls; nine had dementia / memory problems; and 16 experienced difficulties associated with both falls and dementia / memory problems. 45 had some type of home modification or adaptation in place, while 24 received home care services. At the start of the study: 32 had a pendant alarm only (although 22 people received upgraded telecare equipment through involvement in the study, 15 of whom had had only a pendant alarm previously); 21 had a telecare 'package' (more than two items, including smoke, carbon monoxide, temperature extremes or flood detectors); and four made use of a GPS tracking device.[3]

[1] Hamblin et al. (2013) discuss the positive impact of activities on people with a susceptibility to falls or who suffer dementias.

[2] Nicholson (2009) observes that models of frailty rooted in physical deficiencies can oversimplify older people's experiences. Other AKTIVE Working Papers address this by considering the psychological, social and environmental impacts of bodily frailty on older people in the study.

[3] For full characteristics of the AKTIVE sample, see Yeandle (2014a).

# 2 The impact of bodily frailty on everyday activities

The older people in the AKTIVE study, all of whom were living at home (often without a co-resident carer or home care support), spoke about a wide range of everyday activities which they greatly valued, but which they were constrained in undertaking, or unable to continue with, because of specific types or combinations of bodily frailty. Analysis of their accounts suggests these activities can be split into at least three categories: *personal*, *household*, and *recreational* (Table 4.1). These categories incorporate, and expand upon, those included in the categorisation of 'Activities of Daily Living' (ADLs) and 'Instrumental Activities of Daily Living' (IADLs), widely used conceptualisations that serve as measurements of, respectively, self-care activities and independent daily functioning (Katz, 1983).[4]

## Personal care

Items in the 'personal care' category closely resemble the self-care tasks included in the ADL classification. They include: getting dressed / undressed; bowel and bladder management; and maintaining bodily hygiene. Many older people in the AKTIVE sample, particularly those experiencing constrained dexterity, mobility limitations and / or cognitive impairments, found it difficult to conduct personal care tasks without appropriate support (Table 4.1). Some felt that to accept the assistance of carers and / or care workers with personal care undermined their basic competences or dignity (for example, being unable to wash / dress oneself), while the presence in their homes of adaptations and community equipment designed to assist them with self-care tasks felt, to some, like an invasion of their home environment (even though many relied on these to manage personal care).

Some women in the study exemplified the vulnerabilities which can arise from bodily frailty which reduces capacity to manage personal care. Mrs Barnard was 89, had dementia and lived with her daughter in Leeds.[5] She was visited daily by female care workers, arranged, she said, partly to enable her daughter to remain in paid employment. She disliked them helping her wash, however, as she felt self-conscious about her ageing body, compared with their youthful ones. For others, pride in a previously active life made changes arising from bodily frailty difficult to accept. Mrs Hall, a former healthcare professional, spoke of the shame she felt at being unable to attend to her personal care. She resisted having care worker support until her daughter-in-law felt she could no longer provide adequate care and continue in her paid job.

> Interviewer: *Is that the way you've always been – quite independent, self-sufficient?*
>
> Mrs Hall: *Yes. That's how I really prefer to stay. But I do realise that really I can't do everything for myself much longer, I do know that. I've been giving it a lot of thought and I shall have to give in and say yes [to care worker support] before long.*
>
> Mrs Hall, 77, falls, living with her daughter-in-law, Oxfordshire

[4] ADLs consist of washing the body, bowel and bladder management, dressing, eating, functional mobility, personal device care, personal hygiene and grooming, and toilet hygiene. IADLs consist of housework, taking medications, managing money, shopping, using telephone (or other forms of communication), using (appropriate) technology, and transportation within communities.

[5] See the Appendix to the AKTIVE Working Papers for a summary of each research participant's characteristics and of the data available which relates to them. All names used are pseudonyms.

Both these women eventually accepted formal support and recognised that this enabled a family member to maintain valued aspects of their own life. While older people in the study commonly felt that their increasing bodily frailty made this necessary, many felt frustrated by their perceived lack of agency while simultaneously not wanting to become a 'burden' to others (often giving the latter as their main reason for, often reluctantly, accepting home care or similar support).

Table 4.1
Bodily frailties and conditions reported by research participants and activities affected

| Bodily frailty[1] | Associated conditions | ADLs / IADLs | Daily activities affected |
|---|---|---|---|
| **Constrained mobility** | Arthritis, spinal disorders, loss of limb/s, hip problems, fractures / breaks, osteoporosis, stroke / paralysis, conditions affecting balance, fear of falling | ADLs | **Personal**: washing, dressing |
| | | IADLs | **Household**: cooking, cleaning house, carrying out repairs, moving around home, gardening |
| | | IADLs | **Recreational (communal)**: walking, driving, travelling, shopping, participating in leisure activities / sport, staying away from home (e.g. holidays) |
| **Constrained dexterity** | Arthritis, tremors, side-effects of medication, coordination problems, lack of grip / weakness of hands, loss of physical sensation | ADLs & IADLs | **Personal**: washing, dressing, taking medication, feeding oneself |
| | | IADLs | **Household**: cooking, cleaning house, carrying out repairs, gardening |
| | | | **Recreational (private)**: practising hobbies |
| **Sensory impairments** | Visual impairment / blindness, hearing difficulties / deafness, conditions affecting balance, dizziness | IADLs | **Recreational (private)**: reading, watching TV / listening to radio |
| | | IADLs | **Recreational (communal)**: walking, driving, travelling, socialising |
| **Cognitive impairments / memory problems** | Dementias, Parkinson's Disease, alcoholism, brain injuries | ADLs | **Personal**: washing, dressing, taking medication, feeding oneself |
| | | IADLs | **Household**: cooking |
| | | IADLs | **Recreational (communal)**: walking, shopping, travelling, socialising |
| **Psychological difficulties** | Depression, anxiety, panic attacks, schizophrenia, personality disorder | IADLs | **Personal**: being alone, going out, conducting everyday tasks |
| | | | **Recreational (private)**: practising hobbies |
| | | | **Recreational (communal)**: socialising |
| **Other health problems** | Heart conditions, respiratory problems, cancers, diabetes, blood disorders, enuresis | | **Personal**: diet, exercise |
| | | IADLs | **Recreational (communal)**: walking, driving, travelling, socialising |

Source: AKTIVE interviews with older people.

Notes: [1] All information is based on subjective perceptions of older people in the AKTIVE study; these include some conditions that predated later life.

## Household activities

Items in the 'household activities' category are similar to the activities identified as IADLs, and older people in the AKTIVE study reported that some bodily frailties affected these (Table 4.1). Most wished to continue living independently in their own homes; for many, this was not only about avoiding alternatives considered undesirable (such as moving in with relatives, to sheltered housing or into residential care), but also about attending to, and often enjoying, domestic activities that had been an important part of their earlier lives.

Some older people, particularly men, felt frustrated that they were no longer able to tend their gardens. Mr Crow felt that mowing his lawn was an important way of getting exercise, strengthening his muscles to reduce pressure on his damaged hips. Although this activity became increasing difficult as the AKTIVE study advanced, it had given him great satisfaction.

> *I've got a little garden* [in] *which I, you know, grow some spuds and beans and peas and carrots … As long as I'm able, as fit as I am now, and I'm never going to get any fitter than that, I'm happy. I'm happy to do that and continue doing it.*
>
> Mr Crow, 78, falls, living alone, Oxfordshire

Mr Shaw (73, falls, living alone, Oxfordshire) spoke about his work, a core component of his identity. He had been active all his life (and claimed he would still be in paid employment if not for bodily frailty). After a series of falls, resulting in spinal damage, he could no longer attend to his garden. He found this upsetting because he had once been proud of it and now felt embarrassed by its unkempt condition.[6]

A similar desire to remain active and in control of the home was seen among those older people who were trying to continue with housework tasks. Spinal problems meant Mr Hodgkins now used a wheelchair. He had been proactive in trying to continue daily activities (for example, purchasing a lightweight cable-less vacuum cleaner), but grew unhappy when he found he was unable to perform certain domestic tasks, particularly those he believed would keep him active and avoid undesirable aspects of older age:

> *I do a lot of cleaning myself. I get my duster out, but it's not like being able-bodied … It keeps you occupied as well, it keeps you active. I wouldn't like to be like a zombie and not doing anything, because I'm dreading getting any older really, because I'm thinking to myself, oh my God, if I get Alzheimer's, I don't want to go in a bloody home …*
>
> Mr Hodgkins, 70, falls, living alone, Leeds

Following a series of collapses resulting in loss of consciousness and (on one occasion) a kitchen fire, Mr Eaves (77, falls, living alone, Leeds) no longer prepared any food other than slow-cooked meals unlikely to lead to burning. Although he appreciated support from a friend (who checked he had food available) and neighbours (who occasionally prepared meals for him), Mr Eaves (a former lecturer) felt that as a result of bodily frailty he was '*being forced in little ways to become dependent on someone else*'. He lamented this situation, as he remained a keen scholar and believed that, as an older person with great knowledge and experience, he had much to offer his community.

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[6] As also discussed in Yeandle (2014b, Paper 2) some older people in the AKTIVE study who experienced mobility / dexterity problems paid privately for the services of gardeners, or sought the assistance of family or friends (which in some cases they paid for).

## Recreational activities

While 'personal' and 'household' activities reported in the AKTIVE study are similar to ADLs and IADLs, this third category includes some activities not identified in those conceptualisations, but which older people claimed were equally important to them in their everyday lives. Practising their hobbies was a valued activity for many research participants (Hamblin, 2014a, Paper 5 addresses the impact of a loss of activities on older people's identities). For most, these were activities developed earlier in life and included reading, painting, sewing, baking, photography and computing. Some older people continued practising their hobbies, as bodily frailty did not affect their ability to do so; Mrs Robinson (77, falls, living alone, Oxfordshire) overcame some of her feelings of loneliness by making patchwork quilts. Others found this more difficult. The bodily frailties which most commonly limited hobby activities were impaired dexterity, particularly weakness in, or problems in using, the hands; and sensory and / or cognitive impairments, particularly problems with vision. Mrs Tyne (94, falls, living alone, Oxfordshire) very much regretted that she had been forced to give up knitting and sewing because her hands shook (Table 4.1). Mr Lindsay (65, living with his wife, Leeds) could no longer read books because his dementia affected his vision to such a degree that he could not perceive written words (he described this problem as having '*dementia in my eyes*').

Some older people affected by bodily frailties found these compromised their ability to engage with their local environments. For example, restricted mobility (particularly inability to walk more than a very short distance) prevented some older people from using local shops, pubs, churches and libraries, from visiting friends or neighbours, or from taking light exercise. For some, no longer being able to drive (often after their driving licence had been revoked on medical grounds) had resulted in a loss of independence and an increasing reliance on others to carry out basic tasks (such as shopping). Mr Fuhrman (93, dementia / falls, living alone, Oxfordshire) decided to quit driving because of concerns about his and others' road safety, but greatly missed the ability to just 'get up and go', especially as he lived in a remote village and wished to stay there (Hamblin, 2014b, Paper 6 addresses the impact of a loss of activities on older people's feelings of independence).

Sensory and / or cognitive impairments could affect the capacity to socialise (Koivunen, 2014, Paper 3 addresses the impact of a loss of activities on older people's social relations). Mrs Bentley (80, dementia, living alone, Leeds) suffered hearing difficulties which complicated her early symptoms of dementia and made it challenging for her to interact with others in her community (for example, while attending church meetings). Before her family intervened on her behalf, acquiring a hearing aid and arranging weekly visits to a community centre for her, Mrs Bentley had become increasingly isolated at home. Other older people feared embarrassment arising from bodily frailty, and for some this was a significant barrier to spending time with others. Mr Maveritt was reluctant to holiday with family members because of a concern that, having only one leg, taking a long time to attend to personal care tasks, and being slow-moving, his mobility problems would prevent them from enjoying themselves.

> *[D]eep down, I think I'd be a little bit of a burden for them, you know, because, with my leg as it is, I can't walk far at all now. And then going away, I'd love to be able to go away where it's warm and put a pair of shorts on. But with my leg being off and* [the other] *being in a long stocking, it'd be too embarrassing for me.*
>
> Mr Maveritt, 71, falls, living alone, Leeds

# 3 Responses to changes presented by frail bodies

Bodily frailty among older people in the AKTIVE study led to a number of difficulties in everyday life, including in managing personal care, looking after the home, practising hobbies, interacting in local communities, and remaining connected to social networks. These changes had often led to increased reliance on other people and particular equipment, sometimes through a mix of informal and / or formal support (Yeandle, 2014b, Paper 2). Those studied nevertheless differed in their responses to these challenges and to the support they needed, or would accept, to help them function in daily life. They have been grouped into those who resisted or accepted changed circumstances, and those who engaged proactively in strategies to remain active.[7]

## Resisters

Some older people had actively resisted changes arising from bodily frailty, sometimes because they felt it was undesirable to receive formal and / or informal support to help them continue daily activities. Mrs Cash considered being frail 'abnormal' and was determined to maintain activities that kept her independent. Following a period in hospital (after simultaneously suffering a stroke, heart attack, pneumonia, and a broken hip), her daily life changed drastically, leaving her unable to drive or to continue with the dancing she enjoyed. Despite her difficulties, she resisted the proposed introduction of home care and remained eager to 'get back to normal'.

> *I can't stay indoors all the time without going, if I want to do something, I want to do it … But it's that bit of independence. This is what I've lost so much.*
>
> Mrs Cash, 76, falls, living alone, Oxfordshire

During the study, she regained some of her capabilities, started to drive again and used social networking technology to interact with others. She was strongly motivated in her efforts to remain active by her caring responsibilities for her adult son, who had learning difficulties and lived nearby.

Mrs Inigo was 77, had dementia and was susceptible to falls, and lived with her daughter in Buckinghamshire. She refused to have a stair lift and some other assistive technology aids as she felt these implied dependency. She was determined to remain independent, which for her included walking her dog in the locality. Her daughter had found it challenging to communicate concerns about her mother's safety, but eventually persuaded her to use a GPS tracking device when she went out, reducing conflict between them.

For other older people, resisting changes arising from bodily frailty was linked to a fear of losing control or of no longer being able to maintain daily activities considered important. Mrs Hibbs wished to remain independent but found this hard because of increasing mobility problems and cognitive impairment. She had been persuaded by her adult daughters to use telecare and give up driving, but felt her judgements were being questioned. Her perceived loss of autonomy increased her determination to remain active for as long as possible and despite her high risk of falling, she had started using public transport to reach places she would previously have travelled to by car, including an airport to take foreign holidays alone.

[7] These three 'ideal type' categories are not intended to be exhaustive and are based only on accounts reported in the AKTIVE study (Yeandle, 2014b, Paper 2 includes further discussion of analysis using 'ideal types').

> *[G]iving up my car is the saddest thing for me because I've lost my independence … [M]y daughters think I shouldn't be driving because I've got arthritis in my knees and controlling the controls [is difficult] … [But] I can get on the bus in Oxford, it takes me to Gatwick, [I] get on the plane and I can do the same coming back.*
>
> Mrs Hibbs, 83, falls / memory problems, living alone, Oxfordshire

Visiting older people in the AKTIVE study over the course of up to a year enabled the researchers to observe some cases where early resistance gave way to acceptance. Reasons for this included: gradual acceptance of different types of support (through positive experiences of them); compromises between older people and those who cared for or supported them, often following some conflict over safely matters; and increased bodily frailty that proved impossible to deny.

## Accepters

Some older people accepted that their bodily frailty required changes in their daily activities. They saw these as a normal, and sometimes inevitable, consequence of the ageing process and responded to steps taken by others to tackle them. Mrs Bates was 88 and suffered from both dementia and susceptibility to falls. She lived alone in Leeds and had regular support from her daughter (who lived nearby) and care workers who visited daily. She had a small telecare package, including a pendant alarm, but found a medication dispenser too complicated to use. She had accepted a diagnosis of dementia, and despite some difficulties in expressing herself clearly, was able to live at home alone without unacceptable risk. Mrs Bates felt her daughter had taken control of her care situation, however, leaving her a mostly passive recipient of support; she was not entirely happy about this, claiming that her daughter was now '*like a schoolteacher*'.

Mrs Davent had a diagnosis of osteoporosis, and following a fall that resulted in a broken heel, received daily visits from care workers (which she paid for) while her house was reorganised (both her bed and toilet facilities were moved downstairs) to accommodate her mobility limitations. Towards the end of the study, she received a grant to install a stair lift and was looking forward to cancelling her home care support and returning her house to its former state. She felt these changes would allow her to attend to her personal care tasks with more dignity.

> *Even if the walk-in shower isn't ready then, I shall still go upstairs because I can go into the bathroom much better than here. Not having a shower [is a problem], but it's better for me to have a proper wash … I won't have the [care workers] then … There's no need … It's lovely.*
>
> Mrs Davent, 82, falls, living alone, Oxfordshire

In these and some other cases in the study, suitable care support packages were established in response to difficulties arising from bodily frailty, which, apart from minor problems, had worked well. There were nevertheless aspects of support which, with a more proactive approach (on the part of everyone involved, older people, those who cared for or supported them and health and social care staff) might have resulted in fewer difficulties. Better coordinated implementation would have helped Mrs Bates feel more in control of her care situation (including learning how to use her medication dispenser). Similarly, if Mrs Davent had received fully integrated care support after her fall (with prompt installation of a stair lift), she might have avoided the disruption of her house being reorganised.

## Strategists

Some older people in the AKTIVE study, and some of those who supported them, had successfully arranged suitable care support before bodily frailties became too advanced to properly integrate and benefit from the changes. These people usually had some advantages or attributes that helped them, or others, establish timely and preventative support.

Having appropriate knowledge of the options available offered some much greater choice and control. This could arise because the older person or those assisting them: had skills or interests in locating appropriate information, often through access to the Internet (or knew someone with these); had access to voluntary sector groups which gave personalised advice; had previously cared for someone (often a spouse) who had required health or social care support (this seemed to give them transferable knowledge); or knew someone who worked in the health or social care sector.

Access to adequate financial resources to purchase appropriate care support was also important for some older people in the study. After privately purchasing the services of a live-in care worker and buying in a range of home adaptations (stair lift, walk-in shower, caddy to assist mobility), Mr Watson, a former academic, could continue living in his large house, enjoy his garden, and keep his mind occupied by practising hobbies (including writing and independent research).

> *What I'm really saying to you is I have managed not to lose my capacity to think, and that's really important … I wrote some guides and that type of thing and I interviewed a lot of people on what they'd done … I did other things and it kept me very interested [in life], you see?*
>
> Mr Watson, 87, falls, living alone, Oxfordshire

By contrast, Mr Shaw (73, falls, living alone, Oxfordshire) exemplified the converse of this. He would have liked to pay for private home care but lacked the money to do so (claiming he was ineligible for free services through the local authority). Unable to buy in support, he felt he had no choice but to sell his home and move to supported housing.

The advantages conferred by knowledge and / or affluence could, for many older people, be matched by timely, strategic support from health and social care professionals. Mrs Barnard was 89, had dementia and lived with her daughter. After she had a stroke which led to a stay in hospital her daughter negotiated suitable support with the help of an experienced occupational therapist, which was regularly reviewed and adjusted. With a closely monitored package of home care, community equipment and telecare, Mrs Barnard felt safe at home and her daughter felt confident enough to remain in her job, explaining: '*It's allowed me to go out to work. [Without care support in place], I would've been terrified, I'd have been absolutely terrified*'.

# 4 Telecare and the daily activities of people with bodily frailty

Many older people in the AKTIVE study had accepted limitations arising from their own bodily frailty, sometimes adopting proactive strategies to address these, and willingly accessing some kind(s) of care support. As well as support provided by carers and (less often) care workers, most older people in the study used a wide range of devices, home adaptations, community equipment and telecare. Well designed 'packages' of care support helped many of them maintain personal, household and recreational activities as they wished.

All older people in the study made use of telecare.[8] This had often been implemented in response to a crisis (such as a diagnosis of dementia or a fall leading to hospitalisation) and was principally used to enhance safety, reassuring the older person, and their families and friends where relevant, that help was available if required. Telecare functioned in a particularly enabling way for some older people in the study, allowing them to continue daily activities they had valued in their earlier lives. Some examples, presented in relation to each type of activity, are included below.

- Personal care: Before having telecare installed, Mrs Tyne (94, falls, living alone, Oxfordshire) had home care in place, but felt uncomfortable being helped with her personal care activities (especially when male care workers attended). A pendant offered her enough confidence to wash and dress herself, and although she still relied on neighbours to check on her daily, she no longer needed formal support and felt she could continue living in her own home without her daughter (who lived some distance away) worrying about her safety and wellbeing. Other older people in the study described similar experiences.
- Household tasks: The installation of a smoke detector connected to a telecare response centre offered reassurance to many older people in the study when they were cooking meals at home. Some were sometimes forgetful about ovens and grills; others, due to their medical conditions, knew they could collapse and lose consciousness which would be particularly dangerous if they were preparing food. The simplicity of these 'passive' environmental sensors (contrasted with the need to make a phone call in a panic) was greatly valued by older people and those who supported them. 'Active' pendants also enabled some older people to carry out household tasks (such as cleaning), with greatly reduced fear about possible falls or injuries, knowing help was immediately available if required.
- Recreational activities: A pendant / falls detector offered Mr Court, who was 82, susceptible to falls, and lived with his wife in Leeds, enough confidence to continue making objects using tools in his garage. Mr Court 'like[d] to keep [his] mind occupied' and greatly valued his creative hobbies, seeing these as a way of remaining actively involved in everyday life. Following a rewarding career that had taken him all over the world, Mr Lindsay who lived with his wife in Leeds and at 65 suffered from early onset dementia, found it difficult to adjust after his diagnosis forced him to quit paid employment. He compensated by taking his dog for long walks in countryside near his home, but his wife was concerned that, as his condition advanced, he might get lost. This problem was solved when a nurse recommended use of a GPS tracking device, which offered Mr Lindsay enough confidence to walk for as long as he wished and his wife comfort in knowing that she could locate him if necessary.

[8] This was a condition of inclusion in the study.

Not all older people in the study experienced telecare as supportive of daily activities, and some found the device(s) they had in place a hindrance. New telecare users often took time to get used to wearing pendants, with daily activities regularly resulting in 'false alerts' due to devices 'getting in the way'. Even after telecare was integrated into their everyday routines, many removed the devices while bathing or washing up after meals (despite having been told they were waterproof). This was problematic because, while carrying out personal or household activities, older people could be particularly vulnerable to accidents that might require a telecare response. Some older people resisted reattaching their pendant, either forgetting or deliberately refusing to do so, because they felt it interfered with their daily routines.

Other older people, both 'resisters' and 'accepters', perceived no potential in telecare to enhance their capacity to engage in daily activities, claiming it made little or no difference to what they could and could not do. Even some 'strategists', despite talking positively about the positive impact of telecare on their feelings of safety, struggled to see how any telecare equipment could help them continue certain activities, particularly if they were seriously constrained by frailty, as some hobbies and household tasks were rendered impossible for them by limited dexterity and / or mobility problems. While only a few older people in the study said their telecare equipment prevented them from performing desired tasks, some pointed out that certain types of telecare were of limited use for certain activities. Several were frustrated that when engaging in activities outside or near their homes, such as working in a large garden or visiting neighbours, they were outside the operational range of their pendant alarm.

Many carers who contributed to the study expressed concern about whether, in the event of a crisis, their older relative or friend would use the telecare they had in place (a particular concern regarding the 'resister' group). Analysis of accounts given in the study indicated that the more familiar an older person was with telecare, the more confident carers were that it would be used appropriately if needed. This suggests that, to help older people continue living independently in their own homes and participating in familiar daily activities, early and strategic implementation of telecare is desirable. This gives time and opportunity to learn how and when to wear / use it (Box 4.1). By contrast, other accounts given in the study indicate that delayed implementation and insufficient learning about how to use telecare equipment leads to undesirable outcomes, including a loss of independence and limitations in carrying out daily activities (Box 4.2).

**Box 4.1 Strategic telecare implementation and its impact on daily activities: Mrs Bentley**

Mrs Bentley (80, living alone in Leeds) was diagnosed with dementia and received a care needs assessment undertaken by health and social care professionals. As her late husband had also suffered dementia and received formal support services, Mrs Bentley's four adult children had an understanding of what was available to their mother. They were keen to get a comprehensive support package in place before her dementia advanced and made learning new skills (and operating equipment) problematic. Mrs Bentley's daughter explained:

> *New things take a while to get used to … We thought it was best to kind of start with things now so that at least in the future she's got knowledge of what to do … So it's not necessarily that she needs it now 'cause we think she's going to fall, but potentially in the future if it happens …*

In the early stages of her illness, Mrs Bentley received daily visits from care workers while adjusting to new circumstances (her memory lapses complicating household tasks). A number of telecare devices were implemented, including a pendant, smoke / carbon detectors, and a GPS tracking device. Once a social worker had assessed that Mrs Bentley was safe to continue living alone at home, care workers were withdrawn and her family modified the pattern of care they had provided until then.

Following this early, strategic intervention, Mrs Bentley had an organised routine of weekly personal, household and recreational activities. In addition to washing and dressing herself at home, she had a laundry day and a cleaning day, all facilitated by confidence arising from use of her pendant. On another day, she went alone to a local hairdressers, using her GPS tracking device as a precaution against getting lost, and on another, she visited a community centre and participated in exercise / relaxation classes. On weekends, she attended (alone or with a friend) a local church service. Her family was keen for her to remain connected to her community and believed it would help delay the progress of dementia.

Mrs Bentley was happy with her care arrangements and accepted the need for support. Her situation demonstrates what can be achieved with a proactive implementation of appropriate care support, including telecare. Despite challenges presented by dementia, Mrs Bentley was able to continue living independently, remain active on a daily basis, and stay connected to her community. Her adult children felt confident that, in the event of a crisis, Mrs Bentley's telecare equipment would allow her to summon their assistance via the response centre. She commented:

> *And it is nice, being on me own, because you never know. I mean do a bit the house up meself, washing and ironing and cleaning up, and at some point you never know if I'm going to fall, so it would be useful, you know, to get somebody* [to help].

**Box 4.2 Missed opportunities during telecare implementation: Mrs Cooper**

Mrs Cooper (68, Leeds) had suffered for years from a medical condition resulting in lack of balance and heavy falls (often while carrying out personal care activities). At the start of the AKTIVE study, she lived alone in a high rise apartment block, had little interaction with her (in her view) non-communicative neighbours, and was visited intermittently by her adult son (her only carer). Following a needs assessment by a social care professional, Mrs Cooper began to receive daily visits from care workers and was issued with both a pendant and a falls detector.

Mrs Cooper's main problem was that her falls often resulted in loss of consciousness, leaving her unable to press her 'active' pendant. However, only weeks after receiving telecare, she decided to stop using the 'passive' falls detector, because, attached to her waist and responding to tilt / angle, it was repeatedly activated while she watched television in a reclining chair and became annoying.

Although a care support package had been established once Mrs Cooper's falls had become frequent, there was no follow-up assessment to modify unsuccessful solutions put in place. Mrs Cooper lacked knowledge of what support was available, and assumed that a falls detector activated by tilt / angle was the only option (in fact, alternative devices respond to acceleration and / or force of impact, either of which would have been more suitable to her lifestyle).

Another problem arising from Mrs Cooper's falls involved occasional incontinence. In these cases, she would have felt undignified if her adult son (her only responder) was called upon to assist and, on one occasion, had asked specifically for the local authority's telecare response centre to intervene. She explained:

> *I got up to go to the loo, fell on the floor … and I just couldn't get up … [When I woke] I was lying in me own urine and oh, I just couldn't do that any more. So I buzzed [the telecare staff]. And they said, 'Well we've got wardens nearer than your son is.' I says, 'Well, fine.' Which is better for me, 'cause I don't know them from Adam, rather than my son picking me up off the floor- which wouldn't have been nice, covered in pee. Embarrassing for a mum.*

However, even if a telecare alert could be raised immediately (by a 'passive' device more suitable for her), Mrs Cooper, commonly unconscious after a fall, would be unable to request this alternative response arrangement.

Because these problems were not addressed, Mrs Cooper felt that she had no choice but to move to sheltered housing, where professional staff could offer support at all times. She had hoped that there, other residents would be friendlier than her previous neighbours, but after moving in (during the AKTIVE study), this proved not to be the case, and despite feeling safer, Mrs Cooper became as socially isolated as she had been in her flat and wished she had not moved.

With a more proactive implementation of telecare, exploring all possibilities, some of Mrs Cooper's problems might have been avoided, allowing her to remain in her own home, receive support from (depending on circumstances) her son or the telecare response centre, and maintain the capacity to attend to personal care activities without fear of suffering indignity after a fall.

# 5 Discussion: the role of telecare in maintaining daily activities

By engaging regularly with older people over a sustained period, the AKTIVE study developed a rich understanding of their everyday lives, including the many activities some undertook and what these meant to them. Consistent with tasks identified in the widely used ADL / IADL conceptualisation, the study showed how the ability to perform personal care activities related to feelings of independence and dignity, and that household tasks were valued as ways of remaining active and maintaining control of personal environments. By focusing on different aspects of older people's lives, the study also identified a range of recreational activities they considered important. Hobbies helped them remain actively engaged in everyday life and mentally occupied; the ability to leave the home (walking or using transport) was also greatly valued as a way of engaging in local communities and neighbourhoods and maintaining social contacts.

Older people differed in their responses to changes in daily activities linked to increasing bodily frailty. For some, perceived compromises in identity and / or loss of autonomy led to resistance, often resulting in conflict with family members or others who supported them, and avoidance or rejection of support put in place (refusal to accept care workers; not using aids or adaptations; or resisting / abandoning the telecare equipment supplied). For others, early resistance was overcome by increasing bodily frailty and / or familiarisation with the support provided. For older people who had more readily accepted enforced changes in their daily activities, strategic implementation of care 'packages' could make a real difference to the things they could continue doing. Those who adopted proactive measures often had access to suitable information (sourced directly or provided by experts); experienced health or social care support; and (in some cases) financial resources adequate to purchase services they wanted. Older people who had time and opportunity to adapt to the changes caused by their increasing bodily frailty were more likely to accept support to help them manage this, as other research on telecare use has also found (Astell et al, 2009; Cash, 2004; McCreadie, 2006), and less likely to feel compromised by others involved in their care who, some perceived, imposed restrictions on the basis of concerns about their safety and well-being.[9]

The study demonstrated how different items of telecare equipment, often provided in combination, could positively impact on the daily activities of older people. For those experiencing difficulties in attending to personal care, 'first generation' devices (commonly, a pendant alarm) could offer confidence in washing and dressing. For those wishing to maintain household tasks, a combination of 'first' and 'second generation' devices (detectors and sensors) could give enhanced confidence in carrying out activities like cleaning and cooking. For those who wished to remain engaged in their local community or neighbourhood, 'third generation' equipment (GPS tracking devices) brought confidence and reassurance. Not all desired activities could be facilitated by telecare, but several older people reported that enhanced feelings of safety arising from telecare use had given them the confidence to try new activities.

[9] The AKTIVE study identified some tensions and conflicts between older people and those supporting them when older people wished to maintain daily activities. Most carers who contributed to the study were supportive of older people's desire to remain independent in their own homes, but many worried about their safety, particularly when they lived elsewhere.

Along with timely implementation of support packages, the study highlights the need for 'holistic' assessment of all aspects of older people's lives, which considers: physical and mental capacity, daily routines, desired activities, support preferences (for example, some older people dislike having care workers enter their homes), household characteristics (type of property; residency status), and the availability of family or carer support. Understanding of these factors can help determine which telecare devices, in which combination, are likely to be most effective, with 'active' devices (such as pendant alarms) suitable in supporting some activities, and 'passive' devices (sensors and detectors) others.

In observing change in older people's circumstances over time, and how bodily frailty (and sometimes recovery) affects activities, perceptions and confidence, the study highlighted the importance of regularly reviewing and adjusting support. Alternative telecare devices may be needed (for example, if an older person loses the capacity to use an 'active' device) or if daily activities result in 'passive' devices being activated inappropriately. Some older people in the study would have benefited from more regular and timely reassessment of their situation, and the introduction of more suitable devices, strategically combined with other forms of support, to help them remain active and independent.

There is evidence in the study to suggest that those older people who had received comprehensive care assessments / 'packages', who had had time and opportunity to adjust to changes arising from increased bodily frailty, who felt in control of their daily lives and activities, and whose carers were satisfied with the support put in place (in some cases enabling them to have a 'life of their own' outside of caring) were more likely to perceive the value of using telecare in an emergency. The older people who reported *not* using telecare during a crisis gave a variety of reasons for this, mostly relating to: their desire to remain independent (for example, trying to get up alone after a fall); forgetting to use the device (through lack of familiarity); concern about bothering either response centre staff and / or their nominated telecare responders; and misunderstandings about what would happen after telecare equipment was activated.

These are all problems that could be overcome by early, strategic implementation of telecare, and which could result in well-established daily activities and routines; shared understandings between older people and those who support them about telecare use; and clear information about how telecare systems work. Although telecare was used in a crisis by older people in the AKTIVE study only occasionally, those able or willing to do so were familiar with the technology, understood what would happen upon activation of the equipment, and felt confident that they would receive suitable and sensitive support.

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