age Cymru

Creating an age friendly Wales

Improving domiciliary care for older people in Wales.

The view of Age Cymru

Case study

Ms R is in her 50s and has been receiving care for more than eight years. She is wheelchair-bound, has diabetes and has had an ileostomy. Her care package had been increased over time to over 60 hours a week, with half provided by social services and the other half from the Independent Living Fund (ILF). Ms R paid for personal assistants to provide her care using Direct Payments.

She was contacted regarding a review of her care package and told that her morning routine would be observed before a decision was made on her care package. This included observing her shower routine (which includes health-related procedures), leaving her feeling very vulnerable and initially refusing to permit this. On the day of the review, Ms R changed her mind as she wanted the assessor to have a full picture of her needs, but the assessor did not observe the shower taking place.

Ms R was expecting some cuts to be made in light of budgetary constraints. However, when she was contacted by the local authority, the outcome was a two-thirds cut in the hours provided by social services, which had the consequence of also leaving her ineligible for ILF support.

Ms R, supported by an advocate, appealed the decision, but lost the appeal having not received full information about the appeals procedure within the timescale for launching her appeal. She has since had to make her personal assistants redundant as she does not have enough work for them and has now cancelled her Direct Payments entirely after the size of her contribution was increased, even though she lives on benefits. She feels she is not receiving the care she needs to allow her a quality of life and opportunity to contribute to the local community as she has always done in the past.

Many of the cuts focused upon time for food preparation even though Ms R has to be very careful with her diet for medical reasons and does not have a kitchen that has been suitably adapted for a wheelchair user. No adaptation of the kitchen has taken place, despite the loss of hours for supporting food preparation. An unsuitable diet causes significant aggravation to Ms R's health problems but she now has to eat ready meals whilst continuing to monitor sugar and salt levels as best she can.

The quality of domiciliary care in Wales

The provision of domiciliary care in Wales faces a challenging future. An ageing population and increasing numbers of people with complex long-term health and care needs would place the current system under pressure, even without the funding pressures confronting local authorities. Local authorities face budget cuts of between 2.4% and 4.5% for the 2015-2016 financial year. Whilst statutory services such as social services have a measure of legal protection, all aspects of local authority activity are coming under increasing scrutiny.

The proportion of the population aged 65 and over in Wales has been growing at a faster rate than the proportion of the population aged between 18 and 64, a trend that will continue in coming decades. The number of individuals aged 65 and above in Wales is expected to increase from around 600 000 in 2013 to almost 900 000 in 2037[1]. The need for social care increases with age, and the number of those aged 85 or over is growing at an even faster rate than those aged 65 plus. Currently almost half of adults aged over 85 are in receipt of local authority social care services, and growing demand will only increase pressure on a system that is already persistently and acutely underfunded.

What is domiciliary care?

The term 'social care' can be used to designate any service designed to help people who have support needs to live well. In the case of domiciliary care, this is a care worker coming into your house to help with fundamental personal tasks including washing, dressing, getting in and out of bed and going to the toilet. Domiciliary care should help vulnerable older people maintain a decent quality of life in their own home.

Growing demand and financial pressures over recent years have led to a reduction in support for people with moderate needs as eligibility criteria have tightened, leading to fewer people receiving social care. Tightening eligibility criteria has almost certainly contributed to increased levels of unmet need, although it is difficult to produce a reliable estimate of this.

Where vulnerable older people are not entitled to care from their local council and are unable to pay privately, they face struggling on until they reach a crisis situation and often have no choice but to rely heavily on family or friends in the intervening period. Many are then admitted to hospital. Such admissions are preventable with earlier intervention to provide support. Over the longer term, providing earlier support should save on the expense of hospital treatment and reduce the number of days that older people spend in hospital.

[1] LE Wales, April 2014: Future of Paying for Social Care in Wales. First report to the Welsh Government

However, we need better quality, better-funded services in order to achieve this goal. The availability of appropriate good quality social care is also essential to removing the 'exit block' that hospitals experience when they are unable to discharge patients who are medically fit to return home but cannot access the care they need to support them to do so.

Case study

Mrs F is in her late 80s and lives alone. She has mobility difficulties caused by arthritis and thus walks unsteadily, with the aid of a walking frame. She also has Irritable Bowel Syndrome and is on medication for stress and anxiety issues. She is unable to stand for long enough to make a cup of tea and cannot walk whilst carrying a hot drink.

In 2014 her 20-minute lunch time visit was withdrawn (although her other two daily visits for personal care were not affected). The lack of this visit made it extremely difficult for Mrs F to cope and led her to rely on neighbours for help with meals, which does not represent a viable long-term solution. Mrs F was not consulted about the change, with her care plan being reviewed after the lunch time call had been withdrawn. Mrs F was not able to be supported by her son during this process, as she would have liked, as the review took place without prior warning or appointment.

Mrs F was informed that she would have to have microwave meals or a pre-prepared meal delivered. Mrs F was concerned about the cost of these meals. In addition, she pointed out that she was unable to carry a hot meal and was consequently advised to move a table into the kitchen, although there is not enough space.

A subsequent assessment by an occupational therapist confirmed the risk of falls and burns as Mrs F was unable to carry anything as she required both hands to use her walking frame. The withdrawal of the lunch time call was inappropriate with regard to the heightened risk to Mrs F's health and well-being as well as not being properly conducted.

The current situation leads to ever-growing pressure upon family and friends to act as carers, providing unpaid care for their loved ones. The Welsh Government defines a carer as "anyone, of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse"[2]. It is these carers, rather than the health and social care systems, who provide the bulk of care to those who need it. Estimations of the value of the contribution of carers of all ages across the UK range from £55 billion[3] to £119 billion[4] annually. Without them, the health and social care systems would be swamped – there are twice as many carers as paid staff working in the combined health and social care systems[5].

[2] Welsh Government (2013): The Carers Strategy for Wales 2013, WG18868
[3] C McNeil & J Hunter (2014): The Generation Strain (IPPR, London): p3
[4] House of Lords Select Committee on Public Service and Demographic Change (14 March 2013): Ready for Ageing? (HL Paper 140): p82
[5] ibid

However, there are many individuals without this support, and this is a challenge that may grow in the future, given the projected increase in demand for carers over the coming decade. Currently more than 6.5 million people across the UK provide care for family members or friends[6], with estimates from Carers UK suggesting that a further 3.5 million carers will be needed by 2037 based on current demographic projections. Even without the demographic challenge, there are limits of what can be asked of friends and family, despite their willingness to give, and carers must not be relied upon to fill the gaps in the provision of social care.

The benefits of good quality, properly funded domiciliary care

- Help with fundamental tasks to facilitate self-care, maintaining health and hygiene.
- Older people able to live independently for longer in their own homes and communities.
- Care can be tailored to meet the specific needs of an individual.
- Fewer crisis admissions and costly healthcare interventions.
- Regular visits, especially from a small number of care staff, provide social interaction for older people living on their own who find it difficult to go out, helping to combat loneliness and social isolation. Loneliness has a recognised negative impact upon health. For people with dementia, the continuity of a small number of carers is particularly important.
- Carers who provide care to a loved one are able to receive either a respite period or may even be able to remain in paid employment, contributing economically and securing their own financial future.

Domiciliary care services face a number of challenges if they are to provide a high quality service to the vulnerable older people of Wales. The care they provide is not 'basic', which suggests it is of a low-level, but rather 'fundamental' – essential to an older person living a more independent life and maintaining their dignity. The relationship between quality and dignity is critical – it is not just about what support is provided, but about the way in which it is provided. To that end, Age Cymru has identified a number of key areas where action needs to be taken if quality domiciliary care is to be provided in Wales:

1. Commissioning practices

2. Workforce – regulation and registration

3. Training and dementia care

4. Joint working

[6] Carers Wales (2014): State of Caring 2014: p3

Commissioning practices

Commissioning practices are fundamental to ensuring a good quality service can be provided. In recent years, a number of problems have highlighted how commissioning has impacted negatively upon the delivery of good quality domiciliary care.

Best known is the impact upon the length of care visits, resulting in the widely reported and much denigrated phenomenon of the 15-minute care call. According to UKHCA7, 4% of visits commissioned in Wales in 2011 were for 15 minutes or fewer. This cannot be considered a sufficient time period for personal care to be delivered with dignity.

We know from our local Age Cymru partners that there is a frustration at the lack of supervision of the work carried out by domiciliary care workers, and perhaps more importantly, the lack of time care workers have with each client. We believe that a task and time based, rather than outcomes-based, approach to care plans and commissioning has resulted in poor practices in some parts of Wales. Many of our local Age Cymru partners are very concerned about the current quality of domiciliary care in their area. Increasing numbers of older people are reporting that their domiciliary care packages are being cut to 15-20 minute calls.

For example, Age Cymru Swansea Bay report that clients are making choices between going to the toilet and getting something to eat, particularly as at least 5 minutes of the call time is taken by completing administrative tasks and call monitoring. Another example was an older person having to have cold baths as there is not enough time to wait for the boiler to heat the water in a 20 minute call.

Case study

Ms T has been disabled since contracting polio as a child. She mostly uses a wheelchair but was bed-bound whilst waiting for home adaptations and a new wheelchair.

Ms T was receiving three daily call cares for a number of years, but was informed that her lunch call would be reduced from 1hr 15 minutes to half an hour and would consist largely of bedpan duties. If carers had time, they could help prepare a simple lunch or microwave meal. Previously carers had helped Ms T to prepare her own lunch, as managing her diabetes is made easier with fresh food. She was concerned about the impact of these changes upon her health, as was her nurse.

The changes to Ms T's care plan took place without her involvement and before an assessment had been carried out and agreed. Ms T did not agree with the outcomes and refused to sign the new care plan. However, the care plan was implemented regardless.

[7] UKHCA (2012): *Commissioning Survey 2012: Care is not a commodity.*

This is clearly unacceptable and it is crucial that urgent improvements are made to the quality of care being commissioned by local authorities in order to maintain dignity.

It should also be remembered that as eligibility criteria have been tightened, care workers are increasingly dealing with the most vulnerable and frail older people who may have multiple healthcare conditions. Purchasing domiciliary care in units of time or simply according to cost makes it increasingly difficult for staff to deliver good quality care in a way that preserves the dignity of the person being supported. The vast majority of care workers are willing and able to provide quality care but the constraints they are facing make it increasingly difficult to do so. Providing quality care takes time. Rushing visits leads to poorer care, negatively impacting on the dignity and potentially the health of the person being supported and demoralising the care worker.

In a recent consultation, the National Institute for Health and Care Excellence (NICE) has suggested that contracts should ensure care workers have enough time to provide a good quality service, "including having enough time to talk to the person and their carer. They should ensure that workers have enough time to do their job without being rushed or compromising the dignity of the person who uses services."[8] It goes on to state that home care visits of less than half an hour should only be used in a very specific set of circumstances amounting to a welfare check on an individual who is in receipt of a more comprehensive care package.

The majority of care workers are now employed by organisations in the private and voluntary sectors. In recent years there has been a shift towards outsourcing the provision of social care services, including domiciliary care, suggesting that this is viewed as a way of driving costs down compared with the alternative of providing in-house services. In Wales, it is noticeable that the number of hours of "home care" provided by local authorities has dropped significantly between 2008-2009 (5,161,195 hours) and 2013-2014 (3,015,532 hours). By way of comparison, the independent sector went from providing 6,582,406 hours in 2008-09 to 10,064,216 hours in 2013-14[9].

Whilst this demonstrates that the total number of care hours provided has actually risen during this time period, there is a risk that tendering for outsourced services on a low or lowest price basis undermines the quality of the service provided. Poorer quality care risks damaging long-term financial consequences for both local authorities and the NHS if insufficient or poor care has been provided[10]. It may also be that the number of hours has been maintained through the provision of shorter call visits, as highlighted above.

The price paid to the service provider by the local authority also has implications for the terms and conditions of those employed in the sector, and can impact upon recruitment, retention and staff morale. The level of pay received by care workers is directly linked to

[8] NICE Draft for consultation, March 2015: Home care: Delivering personal care and practical support to older people living in their own homes.
[9] StatsWales: https://statswales.wales.gov.uk/Catalogue/Health-and-Social-Care/Social-Services/Adult-Services/Service-Provision/HomeCare-by-LocalAuthority-Measure
[10] Unison, 2012: *Time to care*

the price at which local authorities commission domiciliary care[11]. Domiciliary care is a sector in which zero hours contracts and the minimum wage are widespread, impacting upon the financial security of those who are employed on them. As a consequence, recruitment and retention of staff are both difficult.

Inevitably, if there are problems with recruiting and retaining staff, this has implications for the ability to provide continuity in care. According to a report prepared for the Burstow Commission in England, some care recipients reported having more than 50 different care workers in the space of a year. This is especially problematic in light of the fact that an increasing number of those receiving domiciliary care are living with dementia – it has been estimated that up to 60% of domiciliary care recipients could be living with dementia[12]. This presents challenges in the provision of care but also requires continuity in terms of the staff providing care to these people to the greatest extent possible. Unfamiliar faces can lead to confusion, fear and even an exacerbation of difficult behaviour.

In order to ensure the quality of the service that they have commissioned, it is clear that monitoring of contracts after their award is essential. This follow-up is an aspect that the Care and Social Services Inspectorate Wales (CSSIW) has raised with a number of Welsh local authorities in recent years. In terms of both ensuring the quality of domiciliary care being provided where services have been outsourced, assuring that value for money is achieved and gaining oversight of the terms and conditions of the workforce, the importance of contract monitoring cannot be overlooked.

[11] Unison, 2012.
[12] UKHCA (February 2013): UKHCA Dementia Strategy and Plan

1. Workforce, regulation and registration

We have high expectations of our social care workers, which are not reflected in the way in which the role is viewed in broader terms. The difficulty of doing the job was acknowledged by the Cavendish review:

> **"Helping an elderly person to eat and swallow, bathing someone with dignity and without hurting them, communication with someone with early onset dementia; doing these things with intelligent kindness, dignity, care and respect requires skill. Doing so alone in the home of a stranger…when you are only been paid to be there for 30 minutes, requires considerable maturity and resilience."[13]**

Yet society does not always appear to value the contribution that these essential workers make in providing care for the vulnerable. Conducting difficult work for low pay creates problems of recruitment and retention and it is a testament to the dedication of many domiciliary care workers that they continue to do their job. Low pay, in combination with the perceived low social status of the role, is off-putting for many and this is a problem that will only exacerbate the difficulty of delivering quality care as demand grows.

In a Welsh poll conducted by ICM in February 2015, 92% of the 1000 respondents felt that staff providing care to people in their own homes should be registered with an official regulator.

There are, however, ways of valuing staff that go beyond pay[14] and it is worth reviewing calls for a registration scheme for social care workers in this light. Whilst registration of individual workers can help to tackle the issue of standards and inappropriate behaviour, as discussed below, being a registered care worker could help to enhance the status of the role in the eyes of the public.

Whilst we have not yet seen a scandal in the domiciliary care sector on the scale of those that have been uncovered in both residential care and healthcare settings in recent years, sadly this does not mean that there has been none[15]. If anything, the risk may even be higher as a consequence of the fact there is inevitably less opportunity to provide supervision and oversight to a care worker operating alone in the privacy of someone's own home.

The lack of oversight, when coupled with a high turnover within the work force, is viewed as a significant factor exacerbating threats to the human rights of older people[16].

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[13] The Cavendish Review (July 2013): *An independent review into Healthcare Assistants and Support Workers in the NHS and social care settings*: p7
[14] Joseph Rowntree Foundation (April 2014): Pay, conditions and care quality in residential, domiciliary and nursing services
[15] I Koehler (2014): *Key to care. Report of the Burstow Commission on the future of the home care workforce:* p19
[16] *Ibid:* p20

We believe that there is a strong case for the registration of social care workers providing personal care in the homes of vulnerable, and often frail, older people. A registration scheme for domiciliary care workers can:

- ensure that care workers have demonstrated their competence and are suitably qualified and trained
- adhere to a specified Code of Practice
- bring domiciliary care workers into line with other registered professionals.

Registering individual staff members who provide domiciliary care can be used to enhance the status of their profession and ensure that there is adequate protection for people receiving those services. Current legislative provisions appear to provide different levels of protection for groups of vulnerable people. It is also the case that domiciliary care workers are currently significantly less regulated than other groups of professionals, such as security workers and gas fitters.

Training and dementia care

In order for quality care to be provided with dignity, it is essential that care workers receive appropriate training. Training alone cannot ensure quality care, but it can help to increase the confidence of staff in carrying out their jobs and the ability of those staff to do their job to a good standard. Whilst many already do this, it is often a result of their innate personal qualities as much as a consequence of the training that they have received.

Case study

Mrs P is in her mid-80s and has dementia. Her GP suggested to her family she would benefit from domiciliary care. Following a meeting with a social worker requested by her family, it was agreed a maximum of three care workers would be assigned to Mrs P's calls. During the first week, there were six different carers. Carers failed to follow the care plan and notes, and ignored specific instructions left to assist them e.g. regarding gaining access to the house. This is still an issue due to the number of different carers (the record is eleven different carers in one week).

The family feels the care workers were, and continue to be, very task-oriented. Mrs P's experience with the care workers, especially the morning call, can set her mood for the entire day, requiring sensitivity and positivity on the part of staff. The hourly morning care visit was fixed for 8-9am or 8.30-9.30am but arrival times ranged from before 8 until roughly 10.30am. Calls are often not for the full time allocated.

A structured routine is very important to Mrs P's care. For example a bus picks her up to attend a day centre at a specific time two days a week, yet on several occasions carers failed to arrive on time, resulting in the bus leaving without Mrs P, upsetting her and placing additional pressure and worry on the family.

The family is also concerned about the lack of dementia awareness and training related to dementia on the part of care staff. For example, care workers were reporting that Mrs P had eaten breakfast and taken her medications. However, the family were concerned that care staff were merely asking Mrs P and reporting what she told them, rather than overseeing the process. In light of her condition, it is not possible to rely on Mrs P's report of what she has and has not done, underlining the importance of appropriate dementia training for domiciliary care staff, especially when the older person does not have strong family support.

A good example of the importance of relevant training is in the provision of domiciliary care to people living with dementia. Growing numbers of people in receipt of domiciliary care are living with dementia and there is an urgent need for domiciliary care workers to understand how best to support them. Around two-thirds of people living with dementia live in the community, and one-third of these live alone in their own homes[17].

[17] Alzheimer's Society (2014): Dementia 2014: Opportunity for change: p18

It is thus highly probable that domiciliary care workers regularly encounter people who may have difficulty in communicating their needs, may be confused, frustrated or even on occasions aggressive. Knowing how to communicate and respond appropriately is therefore essential to the delivery of quality care[18]. Appropriate support can have a significant impact upon quality of life.

In a Welsh poll conducted by ICM in February 2015, 63% of respondents stated that domiciliary care workers should receive training on dementia[19].

Demands upon domiciliary care workers are changing. As they increasingly work with the most frail and vulnerable older people in our society, the conditions they face are growing in complexity. They cannot be expected to do so without the appropriate training to provide them with the skills that they need to deliver quality care to older people with multiple complex conditions.

[18] Ibid: p28

[19] Making it easily the most popular from the list of options viewed by recipients, which also included awareness of sensory loss, health and safety, moving and handling, protecting people from abuse, supporting people to eat and drink, infection control and first aid.

2. Joint working - health and social care

It is widely recognised that a number of obstacles and challenges to providing quality person-centred care derive from the separation of the health and social care systems. Whilst funding is predominantly centred upon the health service, quality domiciliary care has an important role to play in preventing unnecessary hospital admissions. As funding to local authorities has been increasingly squeezed in recent years, it has become progressively more difficult to maintain levels of care and support for anyone whose needs are not deemed critical. Joint working is regularly proposed as transfers of care between sectors often cause difficulties that can lead to disruption in the provision of appropriate care. The most obvious example of this is delayed transfers of care, where older people who are medically fit to be discharged are delayed in hospital because they lack appropriate social care support that would allow them to return home.

Case study

Mrs B is in her 90s and was fully independent until suffering a fall which saw her admitted to hospital. She retains full mental capacity. Following her fall, she experienced a delayed discharge from hospital because no care package was available. In fact, she was in hospital for more than nine months, despite being fit to go home. By the time she was discharged, her health was very poor and she required constant care and specialised feeding.

Subsequently the care provided was very poor, with the result that Mrs B's daughter had to leave her own home in England and move in with her mother in order to monitor the care provided. Problems have included care not arriving on time, leaving Mrs B wet, dirty, hungry and without her medication and on occasion only one care worker has arrived, despite Mrs B needing double-handed care. In addition, although Mrs B is able to sit in a chair, carers don't have time to help her move, leaving her bed-ridden. Inexperienced carers also struggle to administer correct feeding procedures properly.

Unable to resolve the problems the family had with the care provider, Mrs B eventually transferred to the Direct Payment scheme and now receives satisfactory care from an alternative source.

Effective transfers of care are fundamental to minimising disruption to the care of the individual and allowing for the best possible health outcomes, yet coordination is far from seamless in the current situation. In order to provide the best possible care, people need to be the priority, rather than the systems. Many older people rely upon several different professionals, or teams of professionals, a lack of joined-up working between them can have a significant impact upon their daily lives[19]. For this reason, the NHS and social care need to work effectively together.

[19] Age UK (March 2014): Health and care integration (Age UK Policy Paper)

Looking forward

Wales has thus far managed to avoid the dramatic decrease in the number of older people receiving domiciliary care that has been witnessed in England. However, as pressures on local authority budgets remain intense, we must be aware that such a development cannot be ruled out in the coming years. Poor quality, or a complete lack of, domiciliary care only places further pressure upon the healthcare service to pick up the pieces through unplanned admissions and delayed transfers of care.

There is therefore an urgent need to ensure that social care, including domiciliary care, receives sufficient funding, that domiciliary care staff are sufficiently well-trained and resourced to meet the growing demands placed upon them and that they are registered in order to ensure that our vulnerable older people receive the level of protection that they deserve.

Action needed

- A serious funding commitment is required to help address deeply entrenched issues relating to commissioning practices and terms and conditions for care staff.
- Domiciliary care workers should be registered. Registration, which could be qualification-based as will be the case in Scotland, will serve both to ensure the protection of people being supported by domiciliary care and also enhance the professional status of domiciliary care workers.
- Registration should be supported by easily recognised training qualifications and a commitment to continued training.
- There is a need to recognise that the demand for social care will be affected by impact of changes to the environment in which older people live, especially the closure of community facilities and cuts to public transport, which will increase rather than decrease dependence upon health and social care.
- Domiciliary care should be reliable, with care staff turning up at the agreed times and staying for a sufficiently long period to ensure that the agreed care plan is carried out.
- Continuity in care, with the same staff regularly attending the same person, would enable care staff to build up positive personal relationships, in addition to combating social isolation. It should be noted that continuity is particularly important when providing care to those living with dementia.
- Health and social care should be integrated to tackle the fundamental imbalance between the two. Social care can relieve the burden on the NHS, but this will require structures and budgets that permit effective joint working and focus on providing person-centred care.

age Cymru

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Join us on our journey to create an age friendly Wales

Tŷ John Pathy, 13/14 Neptune Court
Vanguard Way, Cardiff CF24 5PJ
Tel: 029 2043 1555
www.agecymru.org.uk

www.agecymru.org.uk

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