Public Policy Statement

Health Services and the NHS

May 2016

Summary

The population in Wales has the highest proportion of older people in the UK and health services need to adapt and respond to the fact that more people are living longer, often with chronic conditions. Older people are the main adult users of most health and care services. From education and training to the organisation of care, however, the NHS and health services often do not appear to be designed with older people in mind.

Older people, wherever they live, should have free and fair access to health and care services that maintain and promote their physical, spiritual and mental health, treat illness and support those living with chronic conditions. This principle applies to all older people whether they are in their own homes, in care homes or in hospitals. Health services should be designed to support people's well-being and independence, but our NHS too often appears to be set up purely to treat illness on a 'condition-specific' basis with a goal of 'curing disease', rather than focusing on needs of the person in an holistic manner.

The prevalence of chronic conditions increases with age. Two-thirds of the population of Wales aged 65 or over report having at least one chronic condition, while one-third report having multiple chronic conditions[1]. The Auditor General's 2008 report[2] on the management of chronic conditions concluded that too many patients with chronic conditions were treated in an unplanned way in acute hospitals, accounting for one in six of all emergency medical conditions.

GPs sometimes appear reluctant to refer older people for treatment, describing issues as an "inevitable part of old age and not worth specialist attention". On the other hand, when admission does occur, often as an emergency, there can be a tendency to seek out and treat every other possible condition – something which may be neither wanted nor necessary.

In 2015, the Welsh Government refreshed its position on primary care[3], envisaging a more 'social' model of health that promotes physical, mental and social wellbeing, not just the absence of ill health. The plan also called for a further shift in resources towards primary care over the next four years and away from the more traditional focus on hospital-based care.

There remains a need to change from a reactive crisis management approach to a more proactive, coordinated and preventative approach to allow more people to be cared for closer to, or in, their own home. It is also essential that we get the basics

[1] Wales Audit Office (2014): *The management of chronic conditions in Wales – an update*
[2] Wales Audit Office (2008): *The management of chronic conditions by NHS Wales*
[3] Welsh Government (2015): *Our plan for a primary care service for Wales up to March 2018*

right in delivering health care, and driving up standards and quality to ensure older people in Wales can be confident they will receive dignified care in all settings.

Summary of Public Policy Proposals

General

- Older people must be at the centre of all decisions and developments that impact upon their health and wellbeing and their ability to access NHS services.
- Independent advocacy must be available where needed to ensure older people are supported to make, or engage with, decisions that affect them and their ability to access health services.
- The Welsh Government should ensure that health service policy is robustly monitored to ensure quality standards are maintained.

Dignified Care

- The Welsh Government must ensure that, following the Andrews Report spot checks, vigilance is maintained to ensure its recommendations continue to be implemented. Robust systems to ensure the identification of failures in fundamentals of care – such as those found by the Andrews Report – should be in place, as should sanctions to deal with any breaches.

Hospital Services

- Welsh Government must ensure that Local Health Boards comply with sustained implementation of the recommendations of the 'Trusted to Care' report, and attain consistent standards of hospital care across Wales, through effective and continued monitoring. Special care must be taken to monitor progress in improving dementia care, ensuring adequate nutrition and hydration and appropriate continence care.
- Access to independent advocacy services must be available for those who need it in hospitals across Wales.
- Reablement services should be offered on discharge from hospital where appropriate and NHS staff must work with local authorities to ensure older people are discharged in a timely, safe and appropriate manner.

Nutrition

- Older people should be assessed for risk or signs of malnourishment on admission to, and at regular intervals during, a stay in hospital. Health and social care providers (including community care staff) should be trained to recognise malnutrition, identify any necessary support with eating, drinking or feeding and swallowing, and ensure older people receive that support.
- The Welsh Government should undertake robust monitoring of the All Wales Nutritional Care Pathway in hospitals across Wales.
- The Welsh Government should ensure that public information is produced on the signs and risks of malnutrition to raise public awareness of the issue and improve early detection.

GP Services

- It should be a priority for NHS Wales that all patients have timely access to a GP when needed.
- GPs should look to simplify their appointments booking systems where possible.

Community Services

- Local Health Boards must develop fully costed plans that identify the investment required to rebalance services towards the community.
- Each Local Health Board should clearly identify how the intended shift of resources to the community sector will be achieved in practice and the impact monitored.

Care Homes

- People who live in care homes have exactly the same rights to NHS care as people living in their own homes, and should have access to a GP, pharmacist and referral to specialist services and hospital care when necessary.
- People who live in care homes should have their medicines reviewed annually in order to manage the effects of polypharmacy.

Workforce

- Pre-registration nursing programmes should include specific content on ageing and the needs of older people. Every Local Health Board should have at least one consultant nurse specialising in care of older people.
- Local Health Boards should implement mandatory human rights, dignified care, and dementia care training for frontline health and social care staff in Wales. This should include respectful communication, protecting privacy, promoting autonomy and addressing basic needs such as nutrition and personal hygiene in a sensitive manner.
- The Welsh Government must work with Local Health Boards to ensure there are appropriate staffing levels in all care settings at all times. Trained volunteers can be better utilised, where appropriate, to support patients.
- Health and social care providers must be trained and educated on equality and diversity issues, including awareness that certain faiths or ethnic minority groups may have specific needs. All service providers should consider how the practice of spiritual care can be developed and supported so that spiritual needs at the end of life can be built into all aspects of care.
- In developing and reviewing their Integrated Medium Term Plans, Local Health Boards should map the capacity and capability of their current community workforce to inform workforce plans and to match resources to need.
- Local Health Boards should also map the Welsh Language capacity of their workforce. It is important that older people who speak Welsh as their first language are accommodated and supported by health care services to communicate in Welsh.

Dementia

- Welsh Government must set longer-term targets for a significant improvement in early diagnosis rates for dementia in Wales, and look to Belfast in Northern Ireland for lessons in how they have achieved 70% diagnosis rate and monitor progress towards achieving them.

- The Welsh Government should lead a programme of public awareness activity on the symptoms of dementia, the importance of an early diagnosis and where to access help and support.
- The Welsh Government must improve education and training for health and care staff on recognising, understanding and managing dementia-related conditions. All pre-registration nursing programmes should cover specific content on ageing including dementia.
- The Welsh Government must prioritise the development of nationwide services for early diagnosis and intervention in dementia. This includes the provision of additional funding to ensure that older people across Wales are able to access memory clinics and other specialist services in a timely way and to end current variations in services.
- Information and support for those diagnosed with dementia and their carers and families still needs to be improved. All health and care staff must be able to provide appropriate information on and signposting to advice, advocacy and support services.
- The Welsh Government must ensure there is robust monitoring to capture progress towards achieving the dementia-related actions set out in Together for Mental Health and subsequent announcements and to address any failures in implementation.
- Local Health Boards and the Welsh Government should work together to achieve an increase in the number of individual reviews of the use of antipsychotic medication for people with dementia. Overall, we would like to see a marked reduction in the use of such medication in Wales.

Palliative and End of Life Care

- Health and social care providers need to ensure that palliative and end of life care are considered to be an integral part of care planning for all older people with chronic and long-term conditions.
- The Welsh Government must provide direction on effective collaboration between the Local Health Boards and Local Authorities to ensure equal access for older people to hospice care.
- End of life support commissioned by Local Health Boards must include comprehensive support for care home residents.
- All organisations and professionals in contact with older people towards the end of life should adopt a palliative care approach, integrated with curative treatment and care where appropriate.
- Pre-registration training of all health and social care staff must include sufficient time devoted to palliative care and the needs of older people. Professionals should be supported in keeping up-to-date with these issues throughout their careers.
- Do Not Attempt Resuscitation orders (nor the withdrawal of food and water) must not be placed on a person’s medical records unless they and/or their family/carer are aware and have been consulted.
- The Welsh Government must carry out robust monitoring of the implementation, delivery and outcomes of the Together for Health – Delivering End of Life Care plan to determine whether it is delivering real improvements in palliative and end of life care for older people in Wales.

Health Services and the NHS

This policy statement covers:

- Dignified Care
- Hospital Services
- GP Services
- Community Services
- Workforce
- Dementia
- Palliative and End of Life Care

Note: Other health policy is contained with Age Cymru's Health Improvement and Prevention policy statement. Policy on social care is covered in the Social Care policy statement.

Public policy proposals

General

Age Cymru is committed to supporting the founding principles of the NHS. We recognise the absolute value older people place on a universal comprehensive health service which is free at the point of delivery. Funding must be driven by need and optimised to provide the best possible value for money. In the current economic climate, funding decisions may lead to difficult political choices.

The first phase of the reconfiguration of NHS Services was completed in Wales in 2014 and was followed by a review aimed at learning lessons from the consultation and engagement process which reported at the end of 2014[4]. A number of reconfiguration proposals have proven controversial, especially in more rural Local Health Boards, raising questions about the effectiveness of engagement with local populations. The focus of any review of services must remain a better service for people in Wales and it essential that older people are involved in the design of services and all decisions that impact them in a meaningful way. Access to independent advocacy is essential to ensure that older people have the support to engage in decision-making processes, so that decisions being taken about themselves and their care are with them, rather than for them.

Welsh Government has introduced a 'prudent healthcare' approach, a set of principles that are intended to change the way in which health services are used and provided[5]. The four principles of prudent health care are: achieve health and wellbeing with the public, patients and professionals as equal partners through co-production; care for those with the greatest health need first, making the most effective use of all skills and resources; do only what is needed, no more, no less, and do no harm; reduce inappropriate variation using evidence based practices consistently and transparently.

[4] A Lloyd (2014): *Lessons learned independent review into NHS Service Change Engagement and Consultation Exercises by Health Boards in Wales.*

[5] Minister for Health and Social Services (undated): *An NHS for Future Generations- why are we making prudent healthcare happen*. Available at http://www.prudenthealthcare.org.uk/ph/ (visited 27 April 2016)

In other words, prudent healthcare is based upon minimum appropriate intervention, that is not providing treatment where it is unlikely to benefit the patient, or could even do harm. We agree with the principle of timely, appropriate healthcare and of preventing individuals from having to undergo a greater level of treatment than necessary. However, we must ensure that in practice this does not provide a rationale for inappropriate rationing of services and treatments or denial of healthcare to older people who need it. Welsh Government health strategy and policy need to be supported by robust implementation plans with clear lines of accountability to ensure that the intended outcomes are in fact achieved.

Key calls:

- Older people must be at the centre of all decisions and developments that impact upon their health and wellbeing and their ability to access NHS services.
- Independent advocacy must be available where needed to ensure older people are supported to make, or engage with, decisions that affect them and their ability to access health services.
- The Welsh Government should ensure that health service policy is robustly monitored to ensure quality standards are maintained.

Dignified care – overview

The principles of dignity apply equally through all aspects of all health services, although the absence of dignity is often most visible in hospital services. Older people and their families can feel like an afterthought due to poor communication, lack of involvement in decisions about their care and inadequate support with basics such as eating, drinking and using the toilet. Undignified care can be abusive and leave people feeling devalued, disempowered, embarrassed and humiliated.

Treating older people with dignity must be at the top of the NHS agenda – this includes continence care, tackling malnutrition and preventing poor care infringing upon people's human rights. Dignity encompasses principles of respect, sensitivity, compassion and human rights. Sadly, as reports and investigations continue to show, there is still a long way to go before we can be satisfied that older people are consistently treated with dignity and respect in all healthcare settings in Wales[6]. It is extremely frustrating to hear the same problems year after year – urgent action and prioritisation is needed to ensure real, sustained improvement.

The issue of dignified care in hospital is addressed in the section on Hospital Services.

Key call:

- The Welsh Government must ensure that, following the Andrews Report spot checks, vigilance is maintained to ensure its recommendations continue to be implemented. Robust systems to ensure the identification of failures in

[6] See for example, June Andrews and Mark Butler (2014): *Trusted to Care. An independent review of the Princess of Wales Hospital and Neath Port Talbot Hospital at Abertawe Bro Morgannwg University Health Board*; Donna Ockenden Ltd (2014): *External Investigation into concerns raised regarding the care and treatment of patients, Tawel Fan Ward, Ablett Acute Mental Health Unit, Glan Clwyd Hospital*.

fundamentals of care – such as those found by the Andrews Report – should be in place, as should sanctions to deal with any breaches.

Hospital Services

Hospitals are only one part of a network of services that make up the NHS in Wales. Recent Welsh Government healthcare policy recognises the importance of hospitals, but also the need for care to move closer to home so people are treated either at home or closer to where they live[7], whenever possible.

Older people can experience contradictory extremes of treatment. On the one hand, concerns are expressed about over-treatment and over-medicalisation, especially in relation to medication – something that the prudent healthcare approach seeks to address – whilst other older people face barriers in accessing treatments as a result of age discrimination[8].

People aged 60 and above are significant users of hospital services in Wales, accounting for 51% of all procedure episodes in 2014/2015[9].

Avoiding admission

Avoiding unscheduled admission to hospital is a major concern for the NHS because of the impact on the individual admitted, the high cost of emergency admissions, and the disruption that can be caused to elective care.

Older people are at higher risk of unscheduled admission. Research by the Kings Fund[10] shows the difficulties hospitals have experienced in efforts to reduce admissions. The review found there was evidence of positive effect for the following interventions: continuity of care with a GP; hospital at home as an alternative to admission; assertive case management in mental health; self-management; early senior review in A&E; multidisciplinary interventions and telemonitoring in heart failure; integration of primary and secondary care.

Prevention is dealt with in Age Cymru's Health Improvement and Prevention policy statement. Policy on social care is covered in the Social Care policy statement.

In-patient experience

The Wales National Survey (2013/14) found that 91% of people who had attended hospital in the previous twelve months reported that they were satisfied with the care they had received[11]. Nevertheless a series of reviews and reports have demonstrated failings in hospital settings and called for urgent improvements. These include:

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[7] Welsh Government (2015): *Our plan for a primary care service for Wales up to March 2018*
[8] Age UK and the Royal College of Surgeons (2012): *Access All Ages*
[9] NHS Wales Informatics Services (2015): *Total Procedures, Welsh Residents 2014/15*. Available at http://www.infoandstats.wales.nhs.uk/page.cfm?orgid=869&pid=41010&subjectlist=Total+Procedures&patientcoverlist=Welsh+Residents&period=2014&keyword=&action=Search (Accessed 27 April 2016)
[10] Kings Fund (2010): *Avoiding hospital admissions. What does the research say?*
[11] Statistics for Wales (5 February 2015): *National Survey for Wales 2013-14. Health*

- Older People's Commissioner for Wales: Dementia: More than just memory loss[12]
- Donna Ockenden: Tawel Fan[13]
- June Andrews and Mark Butler: Trusted to Care (the Andrews report)[14]
- Patient's Association: The Lottery of Dignified Care[15]
- Older People's Commissioner for Wales: Dignified Care?[16]
- Care and Social Services Inspectorate Wales and Health Inspectorate Wales: Growing Old My Way[17]

Research undertaken in Wales prior to the work conducted by Andrews and Butler found that only 36 per cent of people in Wales were confident that an older person would be treated with dignity in hospital[18].

The Older People's Commissioner's Dignified Care review found the treatment of some older people in Wales to be "shamefully inadequate"[19] and called for fundamental change to ensure that all older people are treated with dignity and respect in hospital. The report details a series of recommendations, including:

- Stronger ward leadership to foster a culture of dignity and respect.
- Regular dementia awareness training and skills development should be a requirement for all staff caring for older people.
- Lack of timely response to continence needs was widely reported and is unacceptable – Local Health Boards should prioritise the promotion of continence and the management of incontinence.

The review found that the best examples of excellent care were being delivered in settings where skilled ward managers were demonstrating strong leadership and were equipped with the knowledge and authority to shape the culture on their wards. Older people with whom we are in touch echo this point. They also tell us that they fell some problems stem from the fact that it sometimes seem as if no-one is in charge of wards and responsible for monitoring the overall standards of care. Wards need to be staffed with the right number and mix of staff to ensure the right level of training and appropriate skills are represented. Workforce issues are addressed in greater detail below.

The Commissioner's follow-up reports conclude that, while progress had been made, the pace of improvement needed to accelerate in a range of key areas such as dementia care.

The 2014 Andrews report, an independent review of the quality of care for older people at the Princess of Wales and Neath Port Talbot hospitals, identified very specific areas where there were failings in the care of older patients, including:

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[12] Older People's Commissioner for Wales (2016): *Dementia: More than just memory loss*
[13] Donna Ockenden Ltd, 2014
[14] June Andrews and Mark Butler, 2014
[15] Patient's Association (2011): *The lottery of dignified care*
[16] Older People's Commissioner for Wales (2011): *Dignified Care? The experiences of older people in hospital in Wales* (and updates in 2012 and 2013)
[17] CSSIW and HIW (2012): *Growing Old My Way: A review of the impact of the National Service Framework for Older People in Wales*
[18] Age Alliance Wales (2012): *Wales: A Good Place to Grow Old?*
[19] Older People's Commissioner for Wales, 2011: 4

- Giving patients their medication
- Ensuring patients were hydrated
- Overusing night-time sedation
- Basic continence care

In response, a series of unannounced spot checks were carried out at 70 adult in-patient ward areas across 20 NHS Wales hospital sites. The review of these spot checks found that good practice far outweighed deficiencies in care[20]. A particular weak area, however, was the management of medicines. It is essential that this work is sustained to ensure that quality care, provided with compassion and respect for dignity, remains a key priority for NHS Wales. The Welsh Government must ensure that appropriate systems for identifying failures are sustained and that sanctions are in place to deal with any breaches.

Growing Old My Way, the CSSIW and HIW report, found that many patients and their relatives felt that staff often talked down to them, were patronising in their attitude, did not pay them sufficient respect, were over-familiar and automatically called them by first or pet names without asking how they wanted to be addressed[21]. Many older people were very concerned that they had no choice over the gender of the nurse caring for them, with a number of ladies in particular reporting that they found it upsetting and humiliating to be bathed and dressed by a male nurse[22].

A research study also identified barriers and enablers to the delivery of dignified care[23]. The barriers included deficiencies in the knowledge and experience of ward staff in areas such as:

- Lack of attention paid to the care needs of older people in educational programmes
- Lack of knowledge of the needs of people with dementia
- Lack of training in relation to the provision of dignified care

It found that enablers of dignified care included:

- Gender-specific washing and toilet facilities
- Appropriate staffing levels to meet the demands of patient care and the use of volunteers to assist staff
- Sensitive delivery of fundamental care, especially the need for privacy
- Courteous and respectful communication practices
- Organisational policies and operating procedures that place patient experience at the centre, including staff appraisals that take account of the patient experience

We believe that better staff training and supervision on maintaining dignity and respecting human rights should be provided to NHS staff. Regular feedback on care standards should be sought from patients and their families and incorporated into subsequent practice. For example, a simple 'exit' form completed at the end of

[20] Welsh Government (2014): *Learning from Trusted to Care. Ministerial unannounced spot check visits. All Wales report*, p4
[21] CSSIW and HIW, 2012: p59
[22] *ibid*
[23] Win Tadd et al (2011): *Dignity in Practice: An exploration of the care of older adults in acute NHS Trusts*

treatment could provide valuable information on the patient's opinion of the quality of care they received.

Continence

Privacy and independence in personal care are essential in helping people to maintain dignity. We are aware of many examples of inappropriate treatment, most of which centre on inadequate support to maintain independence and a lack of staff awareness about, and facilities to provide, an acceptable level of privacy.

The use of block treatments or going to the toilet by the clock rather than time of need is unacceptable. Older people have told us that whilst in hospital they have been told to wet the bed because of staff shortages. Unfortunately, 'forced incontinence' is frequently reported, with people being made to use a commode or incontinence pads rather than being assisted to use the bathroom. We have heard of patients being told off for having an 'accident' when they are incontinent; staff taking so long to bring bed pans that it is too late by the time they arrive; and routine forced catheterisation of patients when it is not required. This can have dangerous consequences, such as older people telling us that they have limited their fluid intake whilst in hospital to avoid the potential for 'accidents'.

Both the CSSIW/HIW report and the Older People's Commissioner's Dignified Care review highlighted that continence was a major issue for many people. It was also identified as a fundamental and essential aspect of care by the Trusted to Care report, with the spot check review assessing whether timely help was given to patients to meet their toileting needs and that incontinence products were being used appropriately. Promoting and maintaining continence where possible is essential as it has a significant impact on an individual's quality of life.

Appropriate hospital discharge

Too many older people are stuck waiting in hospital beds for much longer than necessary, often during complex discussions between different agencies over who should fund a long-term care package. We regularly hear of cases of older people waiting in hospital for a care package, without knowledge of why they are waiting, or any information as to their options and rights in this process. We hear from our local Age Cymru partners that the majority of older people they speak to do not even know that there is a discharge planning process, let alone that they have a right to be involved in it from the point of admission.

At the other extreme, older people are sometimes discharged without appropriate measures taken to ensure that they will be safe and cared for whilst they recover at home. One person told us: "You can be discharged the day after surgery even if you live alone. There was no discussion about who would look after me, how far my family lived from me or if my house was suitable for me…how did they know it was safe for me to go home". Discharges may also take place at inappropriate times, such as at night, causing unnecessary stress and anxiety for those being discharged.

Key calls:

- Welsh Government must ensure that Local Health Boards comply with sustained implementation of the recommendations of the 'Trusted to Care' report, and attain consistent standards of hospital care across Wales, through effective and continued monitoring. Special care must be taken to monitor progress in improving dementia care, ensuring adequate nutrition and hydration and appropriate continence care.
- Access to independent advocacy services must be available for those who need it in hospitals across Wales.
- Reablement services should be offered on discharge from hospital where appropriate and NHS staff must work with local authorities to ensure older people are discharged in a timely, safe and appropriate manner.
- Older people should be assessed for risk or signs of malnourishment on admission to, and at regular intervals during, a stay in hospital. Health and social care providers (including community care staff) should be trained to recognise malnutrition, identify any necessary support with eating, drinking or feeding and swallowing, and ensure older people receive that support.
- The Welsh Government should undertake robust monitoring of the All Wales Nutritional Care Pathway in hospitals across Wales.
- The Welsh Government should ensure that public information is produced on the signs and risks of malnutrition to raise public awareness of the issue and improve early detection.

GP Services

GPs are usually the first point of contact in the NHS for older people. The National Survey for Wales[24] (which surveys people aged 16+) reported that:

- 92% of those who had seen a GP in the previous 12 months were satisfied with the care they received at the last visit. People aged 75 and over were more likely to be satisfied with the care they received from the GP (97%) than younger adults aged between 16 and 24 (87%).
- 38% of people who had visited a GP in the last twelve months reported finding it difficult to make a convenient appointment.

Older people tell us that the main issues for them in regards to GP surgeries include:

1. Appointments systems – there is huge variation and in some practices it is extremely difficult to make a timely appointment with a GP. Inability to access GPs can increase pressure on Emergency Departments and the Auditor General's last report on unscheduled care concluded that there is potential for improved patient experience and reduced pressures on staff by strengthening local arrangements for same day access to primary care[25].
2. Lack of referral to appropriate services – for example, depression is an important issue for many older people. GPs should be more aware of available services and be able to signpost people to support.
3. Accessibility – cuts to public transport and the location of some new health centres can make it difficult for older people to access their local GP surgery.

[24] Statistics for Wales (5 February 2015): *National Survey for Wales 2013-14. Health*
[25] Wales Audit Office (2013): *Unscheduled Care. A Report on Progress*.

Key calls:

- It should be a priority for NHS Wales that all patients have timely access to a GP when needed.
- GPs should look to simplify their appointments booking systems where possible.

Community Services

A lot of care for older people is given outside the hospital with community-based services provided by healthcare professionals but also by (informal i.e. unpaid) carers. Age Cymru supports the position that care should be delivered as close to home as possible, with community care seen as the 'norm' and time spent receiving care in an acute setting kept as short as is safe.

Effective development of community services requires sustained investment and the switch to this model must ensure no adverse impact on patient care. There are concerns that services are being switched without appropriate investment in the community services needed to support such a system or, worse, where support services, including those provided by the third sector, are being cut. There is a need for this switch to be robustly monitored[26].

Many evening and night-time admissions could be avoided with the 24/7 availability of community nursing services. This would prevent situations where hospitals are used as a 'place of safety' because there is nowhere else.

Prevention and screening are covered in Age Cymru's Health Improvement and Prevention policy statement.

Key calls:

- Local Health Boards must develop fully costed plans that identify the investment required to rebalance services towards the community.
- Each Local Health Board should clearly identify how the intended shift of resources to the community sector will be achieved in practice and the impact monitored.

Care Homes

Residents in care homes must receive equal access to healthcare. It is often assumed that care homes provide comprehensive care services, but this is not the case.

Our experience is that there remains significant variation in access to healthcare services for residents in care homes in Wales. Some care homes have a GP allocated to residents or weekly visits from psychiatric staff while others do not.

Variable access to healthcare services gives rise to concerns about whether regular reviews of medication are being conducted consistently in care homes across Wales. A recent report by the Royal Pharmaceutical Society Wales recommended that care

[26] Wales Audit Office, 2014

home residents receive a medicines review upon entering a care home and a minimum of an annual review thereafter[27].

Key calls:

- People who live in care homes have exactly the same rights to NHS care as people living in their own homes, and should have access to a GP, pharmacist and referral to specialist services and hospital care when necessary.
- People who live in care homes should have their medicines reviewed annually in order to manage the effects of polypharmacy.

Staffing and Workforce

The lack of focus on ageing in education and training for healthcare staff is a clear omission given the proportion of older people accessing health and care services in Wales. Issues around dignity, communication and understanding all can be improved with effective staff education programmes.

The Welsh Government must work with Local Health Boards to ensure there are appropriate staffing levels and skill mix in both hospital wards and in community services at all times. Whilst the recent Nurse Staffing Levels (Wales) Act 2016 works to ensure Local Health Boards calculate and maintain an appropriate nurse staffing level in adult acute settings, provisions do not currently extend to other areas such as mental health and community settings or to other important groups of healthcare professionals. Further work is needed to identify appropriate staffing levels and skill mix in community services and care homes in particular. Trained volunteers can be better utilised, where appropriate, to support patients, but should never be used to replace qualified staff.

It is vital that people who speak Welsh as their first language are accommodated and supported by health and social care services to communicate in Welsh. Communication is absolutely key to ensuring that service provision is effective, appropriate and, crucially, person-centred.

Key calls:

- Pre-registration nursing programmes should include specific content on ageing and the needs of older people. Every Local Health Board should have at least one consultant nurse specialising in care of older people.
- Local Health Boards should implement mandatory human rights, dignified care, and dementia care training for frontline health and social care staff in Wales. This should include respectful communication, protecting privacy, promoting autonomy and addressing basic needs such as nutrition and personal hygiene in a sensitive manner.
- The Welsh Government must work with Local Health Boards to ensure there are appropriate staffing levels in all care settings at all times. Trained volunteers can be better utilised, where appropriate, to support patients.

[27] Royal Pharmaceutical Society Wales (March 2016): *Improving Medicines Use for Care Home Residents*

- Health and social care providers must be trained and educated on equality and diversity issues, including awareness that certain faiths or ethnic minority groups may have specific needs. All service providers should consider how the practice of spiritual care can be developed and supported so that spiritual needs at the end of life can be built into all aspects of care.
- In developing and reviewing their Integrated Medium Term Plans, Local Health Boards should map the capacity and capability of their current community workforce to inform workforce plans and to match resources to need.
- Local Health Boards should also map the Welsh Language capacity of their workforce. It is important that older people who speak Welsh as their first language are accommodated and supported by health care services to communicate in Welsh.

Dementia care

Under-diagnosis

It is estimated that more than 45,000 people in Wales are currently living with dementia and this number is expected to increase significantly over the next decade. Wales currently has one of the lowest dementia diagnosis rates of any part of the UK at approximately 43.4%[28], meaning many people living with dementia in Wales have no formal diagnosis. Without this diagnosis, they are denied access to information, support services and potential treatments that could assist them.

People can wait a long time before seeking help, but it can also take a long time to get a diagnosis even once concerns have been raised with health professionals. There are complex reasons behind the low levels and lateness of diagnosis, including low public awareness, lack of GP knowledge or awareness, attitudes of healthcare professionals, reluctance to seek help and capacity within diagnostic services such as memory clinics.

A recent report by the Older People's Commissioner for Wales[29] demonstrates that many of the problems highlighted in the earlier CSSIW and HIW[30] joint review persist. The report highlighted a lack of understanding of dementia and its impact amongst both the general public and health and social care professionals. Whilst campaigns such as Dementia Friends have clearly raised awareness of the condition, many of the participants reported that greater awareness did not necessarily amount to enhanced understanding.

People with dementia and carers also reported making repeated visits to their GP, sometimes over a number of years, before receiving a diagnosis, with some being treated for stress or depression. Whilst participants were generally more positive about their experience in relation to memory clinics, there was variation in the scope of the service provided across Wales, especially for people with early onset dementia. In some areas of Wales, there are also growing waiting lists leading to delays in diagnosis and intervention.

[28] Alzheimer's Society (2015): *Wales Dementia Diagnosis*
[29] Older People's Commissioner for Wales, 2016
[30] CSSIW and HIW, 2012

The available research presents a clear case for developing nationwide services to improve diagnosis rates and early interventions for people with dementia. It also shows that investment in services only needs to achieve a modest increase in the average quality of life for people with dementia, and a 10% rate of diversion of people with dementia away from residential care, to be deemed cost-effective[31].

Wales can learn from the experience of Belfast, where diagnosis rates are higher than elsewhere in the United Kingdom. There is a need to improve diagnosis rates, increase investment in the capacity of memory clinics to diagnose and support those living with dementia and their family/carer(s), ensure quicker diagnosis and address the variation in services and support that exists across Wales.

Hospital care

One quarter of hospital beds and up to 70% of places in care homes are occupied by people with dementia[32]. Attention has increasingly been focused upon the quality of dementia care in acute settings. A report by the Alzheimer's Society[33] revealed unacceptable variation in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland. There are many examples of excellent local action, where the challenges of dementia are being recognised and addressed. However, the report by the Older People's Commissioner revealed a number of instances of poor care, whilst the review of care delivered in the Tawel Fan ward provided examples of extremely neglectful care[34].

Outcomes for people with dementia who are admitted to hospital are markedly poorer than those without the condition. People with dementia stay longer in hospital than others who go for the same procedure. Furthermore, longer stays are associated with worsening symptoms of dementia and poorer physical health, which means that discharge to a care home becomes more likely and that antipsychotic drugs are more likely to be used. As well as the impact upon the person with dementia and their carer(s), this places further financial pressures upon the NHS.

Currently, specialist mental health beds in hospitals are often not equipped to support those with frailty and physical needs, whilst intermediate care services can be reluctant to admit people with dementia. As a result, discharge from hospital becomes extremely difficult, even when it is clear that hospitals cannot provide the most appropriate support for the person with dementia.

Improving the experience of the large number of people with dementia in hospitals is key to improving the NHS overall. If people with dementia were supported to leave hospital one week earlier than they currently do, significant savings might be achievable across the system as a whole. Much of the money currently spent on treating people with dementia in hospitals could be more effectively invested in appropriate community services outside hospitals, as well as workforce capacity and development.

Staff training

[31] S Banerjee and R Wittenberg (2009): "Clinical and cost-effectiveness of services for early diagnosis and intervention in dementia" *Journal of Geriatric Psychiatry*, Vol 24 (7), pp748-754
[32] Alzheimer's Society (2014): *Dementia 2014: Opportunity for change*, viii
[33] Alzheimer's Society (2009): *Counting the Cost: Caring for people with dementia on hospital wards*
[34] Older People's Commissioner for Wales, 2016; Donna Ockenden Ltd, 2014

Many older people with dementia have little or no access to consultant geriatricians and other specialists. Often, and particularly when older people are resident in care homes, their dementia will be diagnosed and managed by a GP, but approximately two-thirds of people with dementia live in the community. It is therefore vital that there is an understanding of the condition amongst general nursing staff, GPs and their staff, social workers and other professionals working in the health and care sector. All health and care staff should also be able to provide appropriate information on dementia and signpost to advice and support services.

In the Older People's Commissioner's 2016 report, concerns were raised by people living with dementia and their carers about the need to improve care for people with dementia, with specific issues being raised about the lack of knowledge of many healthcare professionals. Whilst Welsh Government has encouraged GP surgeries to take up Welsh Government funded dementia training[35], there is clearly a need for improved training and skills development for all staff caring for older people.

Together for Mental Health strategy

We welcome the commitments in the Welsh Government's Together for Mental Health strategy[36] to improve services and support around dementia, especially the recent proposal in the review of the delivery plan to develop a new dementia strategy in 2016. The 2015 commitment to improve diagnosis dementia rates, fund new primary care support workers and publication of steps to reduce the risk of developing dementia are equally welcome. However, it is not clear that the number of primary care support workers (32) is inadequate to deal with the caseload and there is limited ambition shown in the target of improving dementia diagnosis rates to 50% by 2016.

Antipsychotic medication

The misuse of anti-psychotic medication to 'manage' dementia is an issue which needs urgent attention. An independent review for the Department of Health[37] in England found significant issues in terms of both quality of care and patient safety. The review concluded that antipsychotic drugs appear to be used too often and, at their likely level of use, the potential benefits are most probably outweighed by the risks.

Similar concerns have been raised about the over-use of such medication in Wales. The Trusted to Care report raised concerns about the use of antipsychotic medications without a proper risk assessment of the person with dementia. The Royal Pharmaceutical Society[38] recommended that, in care home settings, antipsychotic medicine should not be routinely prescribed to treat behavioural and psychological symptoms of dementia. Where such medicines are required, they should be prescribed at the lowest dose for the shortest time with regular review by an appropriately skilled pharmacist working as part of a multidisciplinary team.

[35] Welsh Government (2 April 2015): "New dementia targets and staff unveiled by Welsh Government". Available from http://gov.wales/newsroom/healthandsocialcare/2015/150402dementia/?lang=en

[36] Welsh Government (2012): *Together for Mental Health – a strategy for mental health and wellbeing in Wales*

[37] S Banarjee (2009): *The use of antipsychotic medicine for people with dementia: Time for action; A report for the Minister of State for Care Services*

[38] Royal Pharmaceutical Society 2016

It is clear therefore that antipsychotic medication should be treated with great caution and that there should be a marked reduction in the use of such medication. NHS Wales should monitor the regularity of reviews of its use; the number of patients taken off the medication at three months (as recommended) and the overall level of use of such medication.

Key calls:

- The Welsh Government must set long-term targets for a significant improvement in early diagnosis rates for dementia in Wales, and look to Belfast in Northern Ireland for lessons in how they have achieved 70% diagnosis rate and monitor progress towards achieving them.
- The Welsh Government should lead a programme of public awareness activity on the symptoms of dementia, the importance of an early diagnosis and where to access help and support.
- The Welsh Government must improve education and training for health and care staff on recognising, understanding and managing dementia-related conditions. All pre-registration nursing programmes should cover specific content on ageing including dementia.
- The Welsh Government must prioritise the development of nationwide services for early diagnosis and intervention in dementia. This includes the provision of additional funding to ensure that older people across Wales are able to access memory clinics and other specialist services in a timely way and to end current variations in services.
- Information and support for those diagnosed with dementia and their carers and families still needs to be improved. All health and care staff must be able to provide appropriate information on and signposting to advice, advocacy and support services.
- The Welsh Government must ensure there is robust monitoring to capture progress towards achieving the dementia-related actions set out in Together for Mental Health and subsequent announcements and to address any failures in implementation.
- Local Health Boards and the Welsh Government should work together to achieve an increase in the number of individual reviews of the use of antipsychotic medication for people with dementia. Overall, we would like to see a marked reduction in the use of such medication in Wales.

Palliative and End of Life Care

Ideally, death should be a supported, dignified process, in the absence of pain and with any spiritual needs met. Everyone who needs palliative care – specialist, tailored care for the terminally ill, including end of life care – should have access to it, regardless of where they live, their age, medical condition or preference over place of death. Palliative and end of life care should be an integral part of care planning for all older people with chronic and long-term health conditions.

Currently, older people experience unequal access to specialist palliative care and to hospices. One reason for this is that chronic illnesses have not traditionally been the focus of specialist palliative care. Yet even older people with cancer may not have

access to specialist palliative care and are more likely than other age groups to die in hospital or in a care or nursing home. Although there has been some change, older people remain under-represented in in-patient hospices.

The higher proportion of older people dying in care homes and the lack of development of palliative care in these settings is another reason why older people may be less likely to receive services. In order to provide good care for people at the end of their lives, care home staff need to receive external clinical support, particularly from GPs. Without this support, symptom relief may be poor and a resident may end up being transferred to hospital to die. Although this may be appropriate in some situations, there continue to be inappropriate transfers to hospitals from care homes. The factors which can influence this process include a lack of forward planning, a lack of knowledge of the older person's preferences, poor links with GPs and a shortage of resources in the care home.

The National Audit's Office report on end of life services[39] suggests a need for greater input from social care into end of life care, specifically to address the following challenges:

- **Place of care**: There is a disparity between preferences expressed by the majority of people to die at home or in a hospice and the numbers actually dying in a hospital
- **Unnecessary care changes**: A significant proportion of people who die in hospital after being admitted from a care home could have died in their residential or nursing home with better support and advice for, and from, care home staff.
- **Inadequate training and skills base**: Only 7% of domiciliary care workers and 5% of care home assistants hold the NVQ Level 3 qualification that includes (optional) training in support for people at the end of their lives.
- **Poor coordination** between health and social care services in planning, delivery and monitoring of end of life care.

Doctors should not make assumptions about a quality of life. In no circumstances should a Do Not Attempt Resuscitation (DNAR)[40],) order to be placed on a person's medical records without their knowledge or consultation, either with themselves or with an appropriate family member. Institutions should not have policies or assumptions that mean that DNAR orders can be placed on the files of anyone over a certain age. If a DNAR is placed on a person's file, it should be regularly reviewed and removed if circumstances change. It is essential that staff receive training in how to communicate with the person and their family in a sensitive and professional manner during difficult circumstances such as these.

The Together for Health – Delivering End of Life Care plan sets out how inequalities in the care provided by NHS Wales will be addressed. We support the key aims, including 24/7 support to all people entering the terminal phase of their illness and that people who wish their care and death to take place at home are supported in this choice. The implementation and robust monitoring of outcomes of the plan will determine whether it results in real improvements for older people in Wales.

[39] National Audit Office (2008): *End of Life Care*

[40] Also known as Do Not Resuscitate (DNR) or Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

Key calls:

- Health and social care providers need to ensure that palliative and end of life care are considered to be an integral part of care planning for all older people with chronic and long-term conditions.
- The Welsh Government must provide direction on effective collaboration between the Local Health Boards and Local Authorities to ensure equal access for older people to hospice care.
- End of life support commissioned by Local Health Boards must include comprehensive support for care home residents.
- All organisations and professionals in contact with older people towards the end of life should adopt a palliative care approach, integrated with curative treatment and care where appropriate.
- Pre-registration training of all health and social care staff must include sufficient time devoted to palliative care and the needs of older people. Professionals should be supported in keeping up-to-date with these issues throughout their careers.
- Do Not Attempt Resuscitation orders (nor the withdrawal of food and water) must not be placed on a person's medical records unless they and/or their family/carer are aware and have been consulted.
- The Welsh Government must carry out robust monitoring of the implementation, delivery and outcomes of the Together for Health – Delivering End of Life Care plan to determine whether it is delivering real improvements in palliative and end of life care for older people in Wales.