Public Policy Statement

Health Services and the NHS

February 2019

Summary-

Older people are the main adult users of most health and care services. The population in Wales has the highest proportion of older people in the UK and more people are living longer, often with multiple chronic conditions which can be managed but not cured. The NHS was originally designed to treat episodes of acute illness and injury, and communicable disease. Although the NHS has been evolving to meet changing health needs for some time, there is an urgent need to increase the pace and scale of service transformation to meet the needs of an ageing population living with non-communicable, chronic conditions.

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 and care services should be designed to support people's well-being and independence, but the NHS too often appears to treat individual clinical conditions, rather than focusing on the person's needs, experiences and preferred outcomes in an holistic manner.

The percentage of people in Wales living with at least one chronic condition increased from 5.1% in 2004/05 to 6.5% in 2014/15, an almost 30% increase. The percentage of people with multiple chronic conditions has increased substantially – by 56%. Hospital admissions for people with at least one of 12 chronic conditions in total accounted for 58% of total inpatient spend in 2014/15, or 72% for those aged 50 and over.[1]

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[2]. The Auditor General's 2008 report[3] 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.

[1] The Health Foundation (2016): *Chart: The rise in people living with chronic conditions in Wales*

[2] Wales Audit Office (2014): *The management of chronic conditions in Wales – an update*

[3] Wales Audit Office (2008): *The management of chronic conditions by NHS Wales*

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 possible clinical condition – something which the older person may not understand, want or consider they need.

In 2018, in its response to a Parliamentary Review,[4] Welsh Government set out a long term future vision of a whole system approach to health and social care, building on prudent healthcare and focussed on health and wellbeing, and on preventing illness. Welsh Government pledged to develop new, scalable models of seamless local health and social care. A National Transformation Programme of targeted funding and resources to accelerate progress, including a dedicated £100m Transformation Fund, is being delivered through Regional Partnership Boards, which bring together health, local authority and Third Sector representatives.

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

[4] Welsh Government (2018): *A Healthier Wales: our Plan for Health and Social 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 work with Local Authorities and the Third Sector to develop fully costed plans that identify the investment required for service transformation.
- 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 implement the Dementia Action Plan, ensure there is robust monitoring by the Dementia Oversight, Implementation & Impact Group (DOIIG) to capture progress, and commission an external evaluation of its effectiveness.
- 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.
- 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.
- Welsh Government and NHS Wales should ensure that care in Welsh is offered proactively, without the added stress of having to fight for it, at a time which is already challenging and difficult.

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.

An outline of health service policy and reconfiguration in Wales since 2014, including prudent healthcare, the Parliamentary Review and *A Healthier Wales* long term plan for health and social care, is attached an Annex A.

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.
- Welsh Government should strongly encourage Regional Partnership Boards (RPBs) to use those powers to build effective relationships with Third Sector partners, if the aim of delivering transformational local services is to be realised.
- 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. Older people are concerned about a culture of 'cover up' amongst NHS staff. They tell us that, in their experience, the NHS complaints procedure is not fit for purpose and does not enable an older person to challenge NHS decision-making.

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[5]. 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 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. Welsh Government's long-term vision for health and care in Wales[6] is of a whole system approach to health and social care; when people need support, care or treatment, they will be able to access a range of services which are seamless, as close to home as possible, and will only go to a general hospital when that is essential. Hospital services will be designed to reduce the time spent in hospital, and to speed up recovery and will be accessed more quickly.

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[7].

[5] 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*.

[6] Welsh Government (2018): *A Healthier Wales: our Plan for Health and Social Care.*

[7] Age UK and the Royal College of Surgeons (2012): *Access All Ages*

People aged 60 and above are significant users of hospital services in Wales, accounting for 53% of all procedure episodes in 2017/2018[8].

Preventing admission

Preventing 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. Patients over the age of 85 spend longer from average from arrival at accident and emergency departments until admission, transfer or discharge.[9] 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.

Disease 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 found that 90% of people who had attended hospital in 2017/18 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:

- 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]

[8] 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=2017&keyword=&action=Search (Accessed 05 February 2019)

[9] Statistics for Wales (2018): *Time Spent in NHS Wales Accident and Emergency Departments, 2017-18*

[10] Kings Fund (2010): *Avoiding hospital admissions. What does the research say?*

[11] Statistics for Wales (24 October 2018): *National Survey for Wales 2017-18 Statistical Bulletin: Hospital and GP Services.*

[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)

- 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:

- 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

[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

[20] Welsh Government (2014): *Learning from Trusted to Care. Ministerial unannounced spot check visits. All Wales report,* p4

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. The NHS Wales PROMs, PREMs and Effectiveness Programme is phasing in the use of Patient Reported Outcomes Measures (PROMs) and Patient Reported Experience Measures (PREMs) to help NHS Wales gain a better understanding of the patient's perspective on services they deliver by providing patients with the opportunity to tell NHS Wales about their health status and experiences of care.[24] The programme is still at an early stage of development and its impact remains to be seen.

<u>Continence</u>

[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*
[24] NHS Wales, *The NHS Wales PROMs, PREMs and Effectiveness Programme,* available at http://www.cedar.wales.nhs.uk/sitesplus/documents/1091/PROMs%2C%20PREMs%20and%20Effectiveness%20Programme%20Leaflet%20E%284%29.pdf

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. People may be discharged too early, leading to readmission.

Over the longer term, there has been a reduction in the number of delayed transfers of care, mainly due to falls in mental health ward delays. The number of delays in 2017-18 are at similar levels to those seen in 2016-17. Betsi Cadwaladr, Abertawe Bro Morgannwg and Aneurin Bevan had the highest number of delays in most months of 2017-18. Abertawe Bro Morgannwg and Aneurin Bevan had the highest

rates per 10,000 population aged over 75 in 2017-18; historically Cardiff and Vale and Cwm Taf had higher rates but they have reduced in recent years.[25]

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[26] (which surveys people aged 16+) reported that:

- 86% of those who had seen a GP in 2017/18 were satisfied with the care they received at the last visit, down from 90% in 2016/17.
- 42% of people who had visited a GP in 2017/18 reported finding it difficult to make a convenient appointment. 23% of those aged 65-74 and 23% of those aged 75 and over found it very difficult to make a convenient appointment. The most common reasons given were the long wait for an appointment (reported by 51% of those not able to book a convenient appointment, or who had found it difficult to do so), not being able to get through by phone (46%), and needing to make an early morning phone call (45%).

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

[25] Statistics for Wales (2018): *Delayed Transfers of Care in Wales*
[26] Statistics for Wales (24 October 2018): *National Survey for Wales 2017-18. Health*

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[27].

2. Timely access to out of hours care, especially in rural areas.
3. 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.
4. 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.
5. The shortage of GPs in Wales.

A Wales Audit Office report on Primary Care Out-of-Hours Services[28] found: patients have generally positive views about out-of-hours services but there is a need to improve signposting and to achieve the national standards on timeliness; notional funding from the Welsh Government has fallen in real terms and services are strained due to morale and staffing issues that threaten the resilience of services; poor information on service quality and performance is hampering the effective governance, planning and management of services at a national and local level; planning of out-of-hours services is not properly integrated with other key services; the new 111 service will address some integration issues but will not solve all of the problems facing out-of-hours services.

The Royal College of General Practitioners Wales highlights underfunding in Welsh general practice and that things need to change,[29] as more of the same will not deliver the best results for an ageing population with an increase in multiple, long-term conditions. Patients need to be able to access services in their community and get help before issues get worse. The RCGP's recommendations for change include increasing training places for GPs, promoting Wales and general practice as attractive career options, improving incentives to keep GPs in the profession, significantly more support for out of hours services and a step change in funding.

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 primary and community care seen as the 'norm' and time spent receiving care in an acute setting kept as short as is safe.

[27] Wales Audit Office (2013): *Unscheduled Care. A Report on Progress*.
[28] Auditor General for Wales (2018): *Primary Care Out-of-Hours Services*
[29] Royal College of General Practitioners Wales (2018): *Transforming general practice: Building a profession fit for the future*

Effective development of community services requires sustained investment and the switch to this model must ensure no adverse impact on patient care. Before the Transformation Programme announced in *A Healthier Wales*[30], there were concerns that services were 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. Welsh Government's Transformation Programme is intended to accelerate the pace of change. There is therefore now an even greater need for new models of service delivery to be robustly monitored[31].

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.

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

Key calls:

- Regional Partnership Boards must develop fully costed plans that identify the investment required to develop new, integrated models of care which transfer services out of hospital and into the community.
- Each Regional Partnership 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 home residents receive a medicines review upon entering a care home and a minimum of an annual review thereafter[32].

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.

[30] Welsh Government (2018): *A Healthier Wales: our Plan for Health and Social Care.*

[31] Wales Audit Office, 2014

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

- 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.
- 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 their new models of health and care services under the Transformation Programme, Regional Partnership 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 53%[33], 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 report by the Older People's Commissioner for Wales[34] demonstrates that many of the problems highlighted in the earlier CSSIW and HIW[35] 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.

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[36].

[33] Alzheimer's Research UK *Dementia Statistics Hub* available at https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk/ accessed 05 February 2019.
[34] Older People's Commissioner for Wales, 2016
[35] CSSIW and HIW, 2012
[36] 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

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[37]. Attention has increasingly been focused upon the quality of dementia care in acute settings. A report by the Alzheimer's Society[38] 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[39].

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

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

[37] Alzheimer's Society (2014): *Dementia 2014: Opportunity for change*, viii

[38] Alzheimer's Society (2009): *Counting the Cost: Caring for people with dementia on hospital wards*

[39] Older People's Commissioner for Wales, 2016; Donna Ockenden Ltd, 2014

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[40], there is clearly a need for improved training and skills development for all staff caring for older people.

Dementia Action Plan

Welsh Government's Dementia Action Plan 2018-2022 (DAP) sets out a vision for Wales as a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities.[41] Major elements of the DAP include: clear evidence based care pathways; 'teams around the individual'; reviews of the capacity and role of dementia support workers; developing an All Wales Dementia AHP Consultant post; scoping access to memory assessment services to those with learning disabilities; and promoting Dementia Friends awareness sessions and educational resources.

To deliver the actions within this plan, Welsh Government is providing an additional £10m a year from 2018-19 onward to support the step change that is needed in this area, using the Integrated Care Fund (ICF) mechanism to distribute a significant proportion of this additional funding.

As a starting point, Regional Partnership Boards are expected to take a fundamental look at the existing dementia services and care pathway in each area and develop services in line with the dementia plan which address these gaps and identify how these services link with those for the elderly population more broadly. The voluntary sector is expected to play a key role. Progress against delivery of the plan is overseen by a Dementia Oversight, Implementation & Impact Group (DOIIG), including people living with dementia and their carers and families.

Wales' first ever Dementia Action Plan is an historic opportunity to improve life for people affected by dementia. In particular, **we welcome**: the overall vision of a dementia friendly nation, as one that is aspirational and worth working towards; a rights-based approach to implementation; the importance of Dementia Friendliness to all elements of the DAP; the funding provided to implement the plan; the inclusion of specific actions for the housing and transport sectors; the inclusion of the John's Campaign as a key objective;[42] respite as a central policy goal; the theme of supporting people to stay at home; the creation of an All Wales Dementia AHP Consultant post; references to under-served populations, such as services for people with dementia with disabilities, and references to the prison population, and that the principles of the *Good Work* Framework[43] would be rolled out further.

[40] 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

[41] Welsh Government (2018): *Dementia Action Plan for Wales 2018-2022*

[42] Age UK*, Implementing John's Campaign*

[43] Care Council for Wales (2016) *Good Work: A Dementia Learning and Development Framework for Wales*

While the DAP is welcome, we have concerns about its implementation. In particular, **we are concerned about**:

- **Engagement:** how third sector and professional bodies are involved with delivering and monitoring implementation of the DAP; lack of consideration of the well-being of carers; lack of inclusion of peer support; lack of consideration of seldom heard communities;
- **Funding:** intelligence we have received that many decisions on utilising the additional funding have already been made by health boards; how we can be sure that the money is being spent on projects to support people affected by dementia and not being used to prop up existing spending; Regional Partnership Board engagement (or lack of it) with service users and carers on how the fund should be used; conflicting stories from different areas as to whether or not the funding allocated has been made recurrent for each project, which has made developing business plans difficult;
- **Seamlessness of services:** how the rights-based approach will relate to safeguarding and the provision of advocacy services; how teams around the individual and the review of the capacity and role of dementia support workers will complement each other, and whether funding is allocated to support this; how Welsh Government will ensure access to respite care beyond signposting; lack of distinction between palliative care and end of life care; lack of consideration of links to care homes; lack of consideration of access to memory services; lack of workforce planning; lack of consideration of ambulance and emergency departments being dementia friendly;
- **Policy Cohesion:** the policy fit with *A Healthier Wales;* lack of clarity on how the DDAIG will monitor actions for housing and transport sectors, and that the *Compendium of Notable Practice* has not yet been published, despite its importance in informing commissioners regarding notable practice to replicate or test;
- **Governance:** how Welsh Government will provide evidence that major elements of the DAP have been completed; lack of data being collected for High Level Performance Measures; the process for creating the All Wales AHP Consultant post, its accountability and its remit.

We believe that Welsh Government should commission external, independent research into the impact of the plan. We would then have a benchmark against which to evaluate the Welsh Government's performance, at both the mid and end points of the plan.

<u>Antipsychotic medication</u>

The misuse of anti-psychotic medication to 'manage' dementia is an issue which needs urgent attention. An independent review for the Department of Health[44] 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

[44] 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*

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[45] 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.

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.
- Welsh Government must implement the Dementia Action Plan, ensure there is robust monitoring by the Dementia Oversight, Implementation & Impact Group (DOIIG) to capture progress, and commission an external evaluation of its effectiveness.
- 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.

[45] Royal Pharmaceutical Society 2016

Welsh language and people living with dementia

As dementia is a condition which affects linguistic ability, people are at risk of losing grasp of their second language, and not providing care in the Welsh language can lead to frustration and to losing dignity and respect. The needs of Welsh speakers living with dementia are not met and even though national policies state that care through the medium of Welsh is a clinical need not a matter of choice, this is not reflected in the grassroots services available.[46]

How people affected by dementia are assessed, and how the medium of assessments can affect the result and the care that they receive subsequently. Assessment and care in Welsh are often not available unless someone asks, which has a negative effect on Welsh speakers with dementia. One example of this was a patient in a care home who did not speak at all as the staff were not aware that he spoke Welsh and had lost his ability to speak English.

The manager of the care home said, "We presumed that he couldn't speak, until one of the managers said a few words in Welsh and he started speaking straight away. Not broken Welsh but fully fluent...the opportunity to speak Welsh had a huge effect on him."

Today, there are more laws, policies and strategies than ever before which recognise the importance of providing services and care through the medium of Welsh. Welsh Government and NHS Wales should concentrate on putting the principles into action and ensuring that care in Welsh is offered proactively, without the added stress of having to fight for it, at a time which is already challenging and difficult.

Key Call:

- Welsh Government and NHS Wales should ensure that care in Welsh is offered proactively, without the added stress of having to fight for it, at a time which is already challenging and difficult.

Palliative and End of Life Care

An estimated 23,000 people in Wales have a palliative care need every year. The number of people dying each year continues to increase. This means that we will see more people living with multi-morbidity and frailty, not necessarily following a typical or predictable trajectory towards death. A 2015 Alzheimers Society and Marie Curie Report[47] identified that increased need can be found within the growing number of deaths recorded with Alzheimer's, dementia and senility as the underlying cause; and an increase in the number of deaths attributed to heart and renal disease.

[46] Welsh Language Commissioner and Alzheimer's Society Cymru (2018): *Welsh Speakers' Dementia Care*
[47] Alzheimers Society and Marie Curie (2015): *Living and dying with dementia in Wales: Barriers to care*

However, at least 6,000 people with life-limiting and terminal conditions are not receiving the expert care they would benefit from.[48]

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.

Doctors should not make assumptions about the quality of a life. In no circumstances should a Do Not Attempt Resuscitation (DNAR)[49],) 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.

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. People with diagnoses such as dementia or heart failure are often referred for expert end of life care in smaller numbers and at a later stage than people with a cancer diagnosis.[50] 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.

A shortage of GPs and Community and District Nurses means people miss out on palliative care delivered at home or in their communities. Perception and understanding about the support available from palliative care and hospice services, both among the public and healthcare professionals, can adversely also affect access to care, leading to late referrals or low rates of referral for specialist support.[51]

Those who are aged over 85 or who live in a care home often struggle to get the right support.[52] 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, and/or be trained in particular clinical skills, such as the use of morphine pumps. Without this support, symptom relief may be poor and a resident may end up dying in great pain, or being transferred to hospital to die. Although the latter may be appropriate in some situations, there continue to be

[48] National Assembly of Wales Cross Party Group on Hospices and Palliative Care (2018): *CPG Hospices and Palliative Care: Inquiry Inequalities in access to hospice and palliative care*

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

[50] Ibid.

[51] Ibid.

[52] Ibid.

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[53] 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.

According to an Alzheimer's Society and Marie Curie report,[54] the work to implement the recommendations of the Sugar Report[55] has put Wales as a nation 'ahead of the game'. Wales was the first of only two nations in the United Kingdom to have a current and overarching delivery plan for palliative and end of life care.

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.

NHS Wales' Palliative and End of Life Care Delivery Plan[56] envisages people being able to end their days in the location of their choice – be that home, hospital or hospice, and to have access to high quality care wherever they live and die, whatever their underlying disease or disability.

The Plan also states that, given the intense pressure on acute hospital beds, there is a need for a wider range of care interventions to be delivered directly to patients in their own homes. There is also a need for greater teaching of relatives and proxies on aspects of care, including basic moving and handling, tailored to the individual's needs. It is unsustainable in the long term to continue to move patients reaching the end of their lives to hospital for interventions and serious consideration must be

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

[54] Alzheimers Society and Marie Curie (2015): *Living and dying with dementia in Wales: Barriers to care*

[55] Palliative Care Planning Group Wales (2008): *Report to the Minister for Health and Social Services*

[56] NHS Wales (2017): *Palliative and End of Life Care Delivery Plan*

given to ways of delivering more interventions in the community for patients of all ages.

The Plan also includes: a programme of education which includes a Workforce Leadership Programme; Advance Care Planning, working to understand the legal framework around decision-making; improving communication with patients through the continued roll out of a Facilitating 'Serious Illness' conversations training programme; digital technology to support patients and enable them to play a part in their own care.

To widen access to palliative and hospice care in Wales, a National Assembly of Wales Cross Party Group on Hospices and Palliative Care report[57] recommends that:

- The Welsh Government ensures that **action and delivery plans** for people with all health conditions that may benefit from a palliative care approach **are joined up**.
- The Welsh Government develops a robust action plan to **tackle palliative care workforce gaps**, identifying District Nursing and community paediatric nurses as a key priority.
- Health boards ensure there is **comprehensive out-of-hours coverage** for people's end of life care across the whole of Wales, including funding paediatric out of hours services.
- Hospices and palliative care providers **educate colleagues** across the health and care sector **about the role of palliative care and the range of services** available to people.

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.

[57] National Assembly of Wales Cross Party Group on Hospices and Palliative Care (2018): *CPG Hospices and Palliative Care: Inquiry Inequalities in access to hospice and palliative care*

- 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.

ANNEX A

NHS RECONFIGURATION IN WALES

First phase of service reconfiguration

The first phase of a reconfiguration of NHS Services was completed in Wales in 2014 and was followed by a review aimed at learning lessons from a consultation and engagement process which reported at the end of 2014[58]. 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.

Prudent healthcare

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[59]. 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.

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.

Parliamentary Review

In 2016, Welsh Government commissioned a cross-party Parliamentary Review of the long term future of Health and Social Care. The report[60] recommended: one seamless care and support system for Wales; a "Quadruple Aim" in which health and care staff, volunteers and citizens should work together to deliver clear outcomes, improved health and wellbeing, a cared for work force, and better value for money; new local models of seamless care, based on national principles; stronger individual and community involvement; urgent alignment of the workforce with new care

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

[59] 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)

[60] The Parliamentary Review of Health and Social Care in Wales (2018): A *Revolution from Within: Transforming Health and Care in Wales.*

models; support to accelerate the pace of change; maximising the benefits of technology and innovation; system redesign; increasing capacity at a national level to drive transformation, and strengthening leadership, and publishing and benchmarking progress.

Welsh Government long-term vision for health and social care

In 2018, in its response to the Parliamentary Review,[61] Welsh Government set out a long term future vision of a whole system approach to health and social care, building on prudent healthcare and focussed on health and wellbeing, and on preventing illness.

To achieve this future vision, Welsh Government pledged to develop new, scalable models of seamless local health and social care, based on ten Design Principles to translate Prudent Healthcare philosophy and the Quadruple Aim into practical tools. A National Transformation Programme of targeted funding and resources to accelerate progress, including a dedicated £100m Transformation Fund, is being delivered through Regional Partnership Boards, which bring together health, local authority and Third Sector representatives. There are plans to increase investment in digital technologies as a key enabler of change, and to invest in the development of the health, social care and third sector workforce, including unpaid carers and volunteers. Continuous engagement and an ongoing conversation with the Welsh population are meant to ensure that everyone has a voice in this whole system approach and how it develops.

The first Transformation Fund grant awards were announced in autumn 2018. Cardiff and Vale Regional Partnership Board's *Me, My Home, My Community* project[62] integrates health and social care to bring care closer to home. The project will receive nearly £7m over two years from the Transformation Fund to change, develop and join up health and social care services, with more emphasis on preventing illness, and shifting services out of hospital to homes and communities.

Governance and accountability of Regional Partnership Boards

Amendments to the Partnership Regulations under Part 9 of the Social Services and Well-being (Wales) Act 2014 increase the numbers of representatives of cared for people, carers and Third Sector organisations on Regional Partnership Boards. Regional Partnership Boards also have powers to co-opt other persons to be members as appropriate.

We believe that Welsh Government should strongly encourage RPBs to use those powers to build effective relationships with Third Sector partners, if the aim of delivering transformational local services is to be realised. Age Alliance Wales has expressed concerns about the transparency and accountability of Regional Partnership Boards and this is a barrier to wider engagement. Age Alliance Wales members also believe that the Third Sector does not currently have parity of esteem with other members, and that they are much less involved in decision making than many had originally envisaged.

Alliance members are aware of current vacancies for Third Sector members on at least one RPB. It is thought, however, this is a consequence of a lack of genuine

[61] Welsh Government (2018): *A Healthier Wales: our Plan for Health and Social Care.*

[62] Welsh Government press release (18 October 2018): *First part of £100m transformation of health and social care announced.*

Third Sector inclusion and support systems, rather than of there being no wish to be involved: if members could be assured that their time would be well spent when taking up such opportunities we are confident such vacancies would not exist.

We hear similar feedback from other Third Sector networks, who report, for example, that organisations do not feel that they have sufficient opportunity to feed in to RPB meetings and there is no clarity around involvement. There is a general concern that items raised by Third Sector representatives at RPB meetings are often dropped, as meeting agendas are so full. There is also a general lack of engagement of the Third Sector between meetings, when most of the work is actually done.

A WCVA project on the effectiveness of Regional Partnership Board engagement with the Third Sector is due to report in spring 2019.

The focus of any service transformation 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.