

Public Policy Statement
Health Services and the NHS
April 2024

Contents

Background	2
Summary	3
Summary of Public Policy Proposals	6
Public policy proposals	11
General	11
Dignified care	12
Hospital Services	13
Hospital Transport	19
GP Services	21
Community care services	23
Care Homes	24
Staffing and Workforce	25
Dementia care	27
Palliative and End of Life Care	34

Background

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.¹

The NHS was originally designed to treat episodes of acute illness and injury, and communicable disease, with patients expected to use NHS services for a relatively short amount of time. Over time the NHS has become increasingly required to treat non-communicable, chronic conditions too – a duty that is only expected to grow as the population grows older and becomes more at risk of long-term health problems. As of January 2024, there were over 755,000 active patient pathways for NHS services in Wales – up from 412,000 only a decade earlier.²

The NHS has been steadily evolving to meet the changing needs of the population, shifting away from purely acute care and building up its capacity to treat more long-term, chronic conditions. However, the pace and scale of this transformation remains limited. This delay is in part due to the ongoing effects of the Covid-19 pandemic, which caused unprecedented disruption to health and care services. The pandemic increased pressures on the NHS drastically, increasing already lengthy waiting lists, impacting upon quality of care and ultimately pushing many people towards private health treatment for the first time in their lives.³ The effects of lockdowns on the physical and mental health of the population also led to further long-term health conditions that continue to impact on the NHS today. Naturally, all of this has contributed to slowing down the rate of transformation of NHS services.

The pandemic also highlighted the need for a more resilient health service, one that could absorb the shock of a global health crisis and still respond to routine health issues. This concern has driven further questions of how the NHS is organised, resourced and staffed, and whether existing models will be able to survive future shocks – whether medical, political or environmental.

Various plans are underway to reform the NHS in Wales to respond more effectively to the changing health needs of the population. First launched in 2021, the Accelerated Cluster Development (ACD) strategy aims to bring different local health services (GP surgeries, dentistry, optometry, etc) together into a single collaborative group, making it easier for patients to access multiple forms of treatment and improving coordination among health practitioners.⁴ However, progress on the ACD remains slow. Another approach to reforming the NHS in Wales has been the rollout of the 111 service, which provides information in the case of urgent but not life-threatening health issues and has been live in Wales since 2022.⁵ The 111 service

¹ Older People's Commissioner for Wales (February 2023), *Understanding Wales's ageing population: key statistics*.

² StatsWales (January 2024), 'Patient pathways waiting to start treatment by month, grouped weeks and stage of pathway', <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Referral-to-Treatment/patientpathwayswaitingtostarttreatment-by-month-groupedweeks>.

³ Age Cymru (2023), 'What matters to you? – Current experiences of people aged 50 and over in Wales'.

⁴ Welsh Government, NHS Wales (2021), *Planning Framework: 2022-2025*.

⁵ Welsh Government (January 2024), *NHS Activity and Performance Summary: November and December 2023*.

has great potential as a means of reducing pressures on emergency care and unplanned hospital admissions, although public awareness of the service remains limited.

These reforms are just the start of a much wider process of realignment that must take place within the NHS. Over the coming years, health services in Wales will need to be transformed, shifting services towards a care model focused on treating long-term health conditions and building resilience to sudden shocks. Changes such as these will be necessary if the NHS is to be able to continue to meet its core principle of offering free healthcare at the point of use into the future.

Summary

In accordance with the founding principles of the NHS, public health services in Wales must be free at the point of delivery and should be funded according to actual need. Older people should be at the centre of decision-making and developments within NHS services, and every effort should be made to engage with older people on decisions that will affect their ability to access healthcare.

Patients have a right to dignity and respect in all aspects of care. While most NHS staff do their utmost to preserve the dignity of patients, pressures on health services and other factors have resulted in a growing number of patients – especially older people – feeling disrespected and even dehumanised by their treatment. The Welsh Government must work with health boards to eliminate undignified treatment within healthcare Wales. An important step towards this goal would be the implementation and monitoring of the Health and Social Care (Quality and Engagement) (Wales) Act 2020. Furthermore, the Welsh Government must continue the rollout of the Llais service across Wales, to provide patients and their relatives with a platform to voice their concerns about the quality of care.

Hospital services form the backbone of NHS services in Wales. However, hospitals that were designed to meet acute care needs now find themselves under pressure as the population increasingly requires treatment for long-term health conditions. These pressures are causing problems for both hospitals and patients, as waiting times lengthen and the quality of care declines (notably in the case of hospital discharge procedures). To meet this changing demand, the Welsh Government must press ahead with its plan to reform health services, bringing in more robust social care and preventative services to limit pressures on hospitals. At the same time, health services must explore ways to limit unplanned hospital admissions, as well as preparing better temporary care for those awaiting treatment. Hospital discharge should take place in a safe, timely and appropriate manner, and should involve the patient in any decision-making.

A reliable, regular and wide-ranging transport network is needed to ensure that patients can access hospital services with ease and on time. The Welsh Government must ensure that public transport networks are well-funded across Wales, especially in rural areas. Patient Transport Services (PTS) must be guaranteed across all health boards, with clear and up-to-date information available to all users – including those who are not online. Funding must also be made available for community

transport links, and for adequate parking facilities for those driving to hospitals and other health centres.

GP surgeries remain the first point of contact for most older people experiencing health problems. At present, GP services across Wales are experiencing chronic staffing shortages and widespread complaints around booking systems, which are often considered inaccessible to older people. The Welsh Government and NHS must address staffing shortages in GP services and press ahead with plans to integrate GP surgeries into the Accelerated Cluster Development plan. GP surgeries must ensure that their booking systems are easy to use and available to all patients, including those who do not use the internet. GP services must also address reported cases of ageism towards older people and their health complaints.

For many older people, it is more appropriate to have care at home rather than in a hospital setting. Regional Partnership Boards (RPBs) must prioritise providing high-quality and consistent at-home care for older people, with care packages built around individual needs and references. To achieve this, RPBs should address staff shortages in community care by reforming the pay scales and career structures of social care, which currently render social care the poorer relation to a career in healthcare. RPBs should also consider emerging 'healthcare at home' medical technology as a means of reducing reliance on community care services and promoting independent living.

There has been increasing demand for care home places in recent years, as the population has grown older and chronic (often multiple) health conditions become more common. However, when a person moves to a care home, they do not lose their right to NHS health care. It is important that people living in care homes have exactly the same rights to NHS care as those living in their own homes, and should have the same access to GP services, pharmacies, mental health support and wider preventative services. More broadly, people living in care homes should be treated as independent adults as much as is possible. Care homes should learn about their residents and help them to live as independently and in a way that is personally meaningful. Care home staff should also guard against the harmful effects of polypharmacy on residents.

Health services across Wales are experiencing a chronic lack of trained, long-term staff. To resolve this, the Welsh Government must work towards carrying out the National Workforce Implementation Plan across the country and work with local health boards to ensure appropriate staffing levels in hospital wards and community care. The Welsh Government should work with the higher education sector to concentrate on training new healthcare staff to work in Wales (particularly staff trained to work on issues that more commonly affect older people, such as dementia), and should reform healthcare pay and conditions to resolve low staff retention rates. People who speak Welsh as their first language must be accommodated and supported by health and social care services to communicate in Welsh, and greater support should be offered to staff seeking to learn Welsh for use in the workplace.

Dementia is becoming an increasingly common health condition and health services must adapt to this challenge accordingly. The Welsh Government must review the implementation of the Dementia Action Plan (DAP) over 2018-2022 and produce a

follow-up plan to continue the process of embedding dementia care in health and social care services. The Dementia Pathway of Standards (DPS) should continue to be rolled out across health boards, and monitoring put in place to ensure that health services meet its standards. The Welsh Government should work towards improving early diagnosis rates for dementia – a process that may involve scaling up the rollout of FDG-PET scanning to improve the accuracy of early diagnoses. Dementia care should be integrated more thoroughly into hospitals and other health centres, via mechanisms such as the Dementia Friendly Hospital Charter and improving dementia training among healthcare staff. The use of antipsychotics to treat patients living with dementia should be scaled down and more tightly regulated, so that such potentially harmful medication is used sparingly and only as a last resort. Dementia care in Welsh should be offered proactively in all healthcare settings.

Palliative and end of life care should be considered an integral part of care planning for all older people with chronic, long-term conditions. The Welsh Government should continue to pursue a proactive approach to palliative and end of life care by implementing the National Institute for Health and Care Excellence (NICE) End of Life quality standard across health and social care services. Do Not Attempt Resuscitation (DNAR) orders must not be placed on an individual's medical records unless they and/or their family or carer have been consulted, and must never be applied as a blanket measure.

Summary of Public Policy Proposals

General

- NHS services must continue to be free at the point of delivery and must be funded according to need, in accordance with the founding principles of the NHS.
- 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.
- Changes to NHS services must be communicated clearly to the public, utilising both online and non-digital channels of communication.
- 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 and NHS Wales must ensure that dignity is maintained across all aspects of health and social care. People of all ages accessing health care in Wales must not be subjected to undignified treatment, nor dehumanising and harmful language. In particular, this includes ensuring clear communication with patients, maintaining their right to privacy, providing adequate food, water and toilets, and using respectful language when talking about patients.
- The Welsh Government should continue to roll out the Llais service across Wales. Llais must be monitored to ensure that people's complaints are taken seriously and acted upon appropriately.
- The duties of candour and quality, as set out in the Health and Social Care (Quality and Engagement) (Wales) Act 2020, must be implemented across all health boards in Wales. The Welsh Government should monitor the implementation process to ensure its success.
- More research should be produced on dignified care across health services in Wales.

Hospital Services

- Plans must continue with reforming the health and social care services with the long-term aim of limiting hospital use to acute healthcare needs, rather than as a catch-all for any health problems. Among other things, this will mean ensuring that adequate and well-funded preventative services are in place in communities across Wales.
- Factors that could help to reduce unscheduled hospital admissions should be strengthened, including increasing public awareness of the NHS 111 line and driving forward the rollout of Advanced Paramedic Practitioners (APPs) across Wales.
- The reduction of post-pandemic hospital waiting times should be prioritised, but not at the cost of quality of care.
- For waiting times of 6 months and over, health services must ensure that patients receive a personalised care and management plan for their waiting time, and

should collaborate with local authority services and the third sector to provide personalised support for those waiting for treatment.

- Patients must be kept in close communication with health services while waiting for hospital treatment, informing them of where they can access support and what measures they can take to manage their symptoms.
- Fundamental standards of dignity should be enforced across all hospitals, including ready access to water, food and toilet facilities, adequate bed and seating space for patients, continence care, basic privacy for medical procedures, and respectful communication with patients.
- Patients should be supplied with adequate information on the treatment they are experiencing, so that they can make informed decisions regarding any medical procedures.
- Hospital discharge should take place in a safe, timely and appropriate manner. The discharge process should account for the personal and social circumstances of patients, as well as medical. Hospitals should maintain a clear line of communication with patients following discharge.
- Patients must be made aware in advance of the hospital discharge planning process and their right to be involved in the process from the point of admission.
- The Welsh Government should undertake an audit of hospital-to-home services to ensure the continued availability and accessibility of these services across all health boards.

Hospital transport

- The Welsh Government must support public transport networks across Wales, to ensure regular bus and train services – including in more rural areas. Public transport must also be easily accessible to users, and transport timetables and other information must be available via both online and offline sources.
- Patient Transport Services (PTS) should be guaranteed across all health boards in Wales, with broad criteria to maximise availability of use. This should be complemented by clear, accessible and up-to-date public information on PTS.
- The Welsh Government should allocate sustainable funding to community transport initiatives (e.g., the Dormant Assets fund) to ensure their continued operation in the long term.
- All hospitals and other health centres must have adequate parking facilities, including accessible parking spaces.

GP Services

- The Welsh Government and NHS must address chronic staffing shortages in GP surgeries across Wales.
- The Welsh Government should press ahead with the Accelerated Cluster Development (ACD) plan, while taking into account the needs of older people (e.g., transport needs, the need for some routine services to remain in the community) in doing so.
- GP surgeries should reform their appointment booking systems so that people are able to book both same-day and advance appointments without issue. Offline options should be maintained for those who are unable to use the internet (or choose not to).

- GP surgeries must work to eliminate ageist assumptions towards older people and their health complaints.

Community care services

- Regional Partnership Boards (RPBs) must prioritise the provision of high-quality, consistent at-home care to older people. Care packages should be built around individual needs, routines and preferences, drawing on support from both health and social care as necessary.
- To facilitate this, there should be greater integration of social and health care in Wales. The development of a National Care Service should be used as a means of promoting social care as an equal partner to health care in the provision of long-term care outside of hospital.
- RPBs must tackle staff shortages in social care by addressing the poor pay and conditions experienced by many carers - working as a social carer should not be considered the poor relation of a career in healthcare.
- Consideration should be given to emerging 'healthcare at home' solutions as a means of reducing reliance on community care, as well as a means of avoiding preventable hospital admissions.

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 (including mental health care) when necessary.
- People who live in care homes should have their medicines reviewed annually in order to manage the effects of polypharmacy.
- Care homes should use the transitional process into a home to learn about new residents in a holistic sense. This can help staff to minimise disruptions to the individual's life and create a care package that is more closely built around their personal background, needs and preferences.

Staffing and workforce

- The Welsh Government must fully implement the National Workforce Implementation Plan to resolve the chronic lack of trained, long-term staff across NHS services in Wales.
- Trained volunteers should be utilised to support patients as part of the Implementation Plan. However, they should never be used to replace qualified staff.
- 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. Further work is needed to identify appropriate staffing levels and skill mix in community services (particularly care homes).
- The Welsh Government should work with Health Education and Improvement Wales (HEIW) and the education sector to address key gaps in training, such as ageing and the needs of older people.
- The Welsh Government and Public Health Wales must explore ways to reform pay grades and career progression in health services, in order to incentivise people to work (and stay) in healthcare.

- People who speak Welsh as their first language must be accommodated and supported by health and social care services to communicate in Welsh. Greater support should be offered to staff seeking to learn Welsh and use it in the workplace.

Dementia

- The Welsh Government must review the implementation of the Dementia Action Plan (DAP) and produce a follow-up dementia plan to continue the process of embedding dementia care as a priority in health and social care services.
- The Dementia Pathway of Standards (DPS) should continue to be rolled out across health boards, and effective monitoring put in place to ensure that services are meeting standards. RPBs must receive the necessary resources to allow services to meet these standards.
- Diagnosis rates for dementia must be improved across Wales. To facilitate this, the Welsh Government should set long-term targets for a significant improvement in early diagnosis rates across all health boards.
- FDG-PET scanning should be scaled up across Wales, in order to provide earlier and more accurate dementia diagnoses, thereby allowing patients to receive support earlier and easing pressure on carers.
- The Welsh Government must ensure that the Dementia Friendly Hospital Charter for Wales is implemented and rigorously enforced across all health boards.
- 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.
- Hospitals, care homes and other care settings should offer non-pharmaceutical approaches to treating challenging behaviours during dementia care. Antipsychotic medication should only be offered as a last resort, and the prescription process should involve an Independent Mental Capacity Advocate (IMCA). Antipsychotic medication use should be short-term and reviewed every 6 weeks.
- 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 in dementia care, 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. This includes preparing the health and social care services for the higher demand for complex palliative care that is likely to emerge in the coming years.
- The Welsh Government should continue to pursue a proactive approach to palliative and end of life care. It should work to implement the NICE End of Life

Care quality standard across health and social care services and monitor their uptake.

- Do Not Attempt Resuscitation (DNAR) orders must not be placed on a person's medical records unless they and/or their family/carer are aware and have been consulted. This also applies to the withdrawal of food and water.

Health Services and the NHS

This policy statement covers:

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

Note: Policy on social care is covered in the Age Cymru policy statements ‘Social care funding’ and ‘Health interventions and preventative services’.

Note: disease prevention, screening and other community health services are covered in greater detail in Age Cymru’s Health Interventions and Preventative Services 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. Because of this, funding for public health services in Wales must be driven by need and optimised to provide the best possible value for money.

We recognise that, in the context of post-pandemic recovery and the rising cost of living, the NHS is in many ways struggling to maintain a service that adheres to its founding principles. Budgetary constraints and staffing shortages make it difficult for NHS services across Wales to meet the healthcare needs of people of all ages, and particularly those of older people, who are more likely to have complex healthcare needs. Notably, 69% of respondents in Age Cymru’s 2023 annual survey reported having a negative experience accessing health services in the last year.⁶ For many, the impression is that NHS services will never return to pre-pandemic standards.⁷

Furthermore, we understand that positive changes within NHS services are not always being communicated clearly to older people. For example, few people are aware that it is now possible to self-refer for physiotherapy in most areas of Wales, suggesting that this change has not been communicated clearly to the public.⁸

⁶ Age Cymru (2023), ‘What matters to you? – Current experiences of people aged 50 and over in Wales’.

⁷ Age Cymru (2022), ‘Current experiences of people aged 50 or over in Wales of the Covid-19 pandemic, and views on the year ahead’.

⁸ NHS 111 Wales (December 2022), ‘Physiotherapy’, <https://111.wales.nhs.uk/Physiotherapy/>.

Despite these challenges, it is vital that the NHS in Wales receives adequate funding to ensure that it can continue to be free at the point of delivery and to be able to meet the health needs of older people in a timely and effective manner. This may mean making difficult political decisions, but we believe that it is of paramount importance for the health and wellbeing of the older people of Wales.

In addition to the issue of funding, there are other central principles that must remain in place to ensure that health services in Wales can continue to support older people. Firstly, independent advocacy must be in place across Wales to ensure that older people are supported to access health services and are able to make, or engage with, decisions that affect their ability to access health services. Secondly, the Welsh Government must regularly monitor health service policy to ensure that quality standards are maintained throughout the NHS in Wales.

Key calls:

- NHS services must continue to be free at the point of delivery and must be funded according to need, in accordance with the founding principles of the NHS.
- 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.
- Changes to NHS services must be communicated clearly to the public, utilising both online and non-digital channels of communication.
- 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

Dignity in healthcare encompasses the principles of respect, sensitivity, compassion and human rights. These principles apply equally through all aspects of all health services, although their absence 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. Similarly, the language commonly used to describe older people accessing healthcare can sometimes dehumanise the patient and make it seem as though they are to blame for failures within the healthcare system. An example that has gained prominence since the pandemic is 'bed blocking', which removes the patient's sense of humanity and suggests that they are individually to blame for delays in transfers of care, rather than systemic failures.⁹

Undignified care can be abusive and leave people feeling devalued, disempowered, embarrassed and humiliated. It is therefore important that people accessing healthcare in Wales have the opportunity to raise any concerns regarding undignified care, safe with the knowledge that their complaints will be taken seriously and acted

⁹ Sebastian Hinde et al., 'Delayed transfers of care for older people: a wider perspective', *Age and Ageing*, 50.4 (2021), 1073-1076.

upon where necessary. In April 2023, the Welsh Government launched Llais, the new independent national body designed to represent the people of Wales in the health and social care.¹⁰ At the same time, it instituted the Health and Social Care (Quality and Engagement) (Wales) Act 2020, which contained duties of candour and quality.¹¹ We welcome both of these measures as tools for maintaining dignified care within the NHS in Wales.

However, efforts must be made to monitor the effectiveness of Llais in representing citizens' voices, as well as to ensure that complaints regarding undignified care are being handled respectfully and effectively. At the same time, the Welsh Government must ensure that the principles of the 2020 Act are being implemented across all health boards in Wales.

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

Key calls:

- The Welsh Government and NHS Wales must ensure that dignity is maintained across all aspects of health and social care. People of all ages accessing health care in Wales must not be subjected to undignified treatment, nor dehumanising and harmful language. In particular, this includes ensuring clear communication with patients, maintaining their right to privacy, providing adequate food, water and toilets, and using respectful language when talking about patients.
- The Welsh Government should continue to roll out the Llais service across Wales. Llais must be monitored to ensure that people's complaints are taken seriously and acted upon appropriately.
- The duties of candour and quality, as set out in the Health and Social Care (Quality and Engagement) (Wales) Act 2020, must be implemented across all health boards in Wales. The Welsh Government should monitor the implementation process to ensure its success.
- More research should be produced on dignified care across health services in Wales.

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 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 and as close to home as possible, and will only go to a general hospital for the treatment of acute health issues.¹² Hospital services will be designed to reduce the time spent in hospital, and to speed up recovery and will be accessed more quickly.

However, the impact of the Covid-19 pandemic and budgetary constraints in recent years have slowed down the implementation of this vision. Hospitals are overly relied upon to meet healthcare needs, despite being originally intended only for acute

¹⁰ Llais (2023), 'What we do', <https://www.llaiswales.org/about-us/what-we-do>.

¹¹ Welsh Government (2023), 'Written Statement: Commencement of the Health and Social Care (Quality and Engagement) (Wales) Act 2020'.

¹² Welsh Government (2018): *A Healthier Wales: our Plan for Health and Social Care*.

medical problems. Factors such as the lack of preventative services and access to GPs mean that many health conditions are not tackled until they reach an acute stage, requiring hospital treatment. At the other end of treatment, difficulties accessing further care (e.g., domiciliary care, care homes, etc) mean that patients are often unable to transfer out of hospital after their acute medical needs have been met. All of these problems tend to affect older people more commonly, as they are more likely to experience multiple health conditions, often at the same time.

The following section explores various recommendations to ensure that hospital services are still able to meet the Welsh Government's long-term plan to transform hospitals into sites of acute medical treatment within a much wider, more specialised healthcare system – while taking into account the considerable pressures experienced by the NHS over the past few years.

Further information on preventative health services is available in the Age Cymru policy statement 'Health interventions and preventative services.'

Preventing unscheduled admissions

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. According to research into NHS hospital use in England, unplanned admissions account for 67% of hospital beds occupied.¹³ Older people are at higher risk of unscheduled admission, primarily because they are more likely to have multiple (and often simultaneous) health conditions.

The most effective way to prevent unscheduled admissions to hospital is to ensure that adequate preventative healthcare is in place across communities. This includes GP surgeries, dentists, podiatrists, physiotherapists and other specialist practitioners, as well as social care and mental health support. It also involves public messaging around healthy living, including on the risks of alcohol and tobacco use and the promotion of healthy lifestyles. Ultimately, increasing funding and support for these preventative services will result in fewer unscheduled hospital admissions, especially among those who may experience multiple health conditions, most notably older people.

For further information on preventative services, see the policy statement 'Health interventions and preventative services'.

Since April 2022, health service users in Wales have been able to access the NHS 111 line, which provides information and advice on urgent but not life-threatening health issues.¹⁴ This service has great potential to reduce unscheduled hospital admissions, as individuals are able to tackle health complaints at home rather than requiring support from hospital staff. However, evidence from Age Cymru's

¹³ John Busby, Sarah Purdy and William Hollingworth, 'Opportunities for primary care to reduce hospital admissions: a cross-sectional study of geographical variation', *British Journal of General Practice*, 65.654 (2017), 20-28.

¹⁴ Welsh Government (April 2022), '111 service now available across Wales', [111 service now available across Wales | GOV.WALES](#).

consultative forums suggests that there is still limited public awareness of the 111 service, even two years on.

Changes to the way that emergency care is applied may also offer means of reducing unscheduled hospital admissions. Emergency departments are hard-pressed in Wales, with the target of addressing 95% of emergency cases within 4 hours being frequently missed (in recent months this rate has sometimes dipped as low as 55%).¹⁵ While increased funding and more sustainable staffing models would greatly help improve the effectiveness of emergency departments, there are alternative changes that could be made to emergency care that could reduce unscheduled admissions. Chief amongst these is the rollout of Advanced Paramedic Practitioners (APPs) – paramedics with additional training advanced clinical decisions, medicine reviews and, in some cases, prescribing medication. According to the Welsh Ambulance Service, 70% fewer people needed admission to hospital after being seen by an APP, rather than traditional paramedic crews.¹⁶ Increasing the number of APPs across Wales could therefore help to reduce emergency admissions, cutting the number of unscheduled admissions to hospitals more generally.

Waiting for treatment

The NHS in Wales has been struggling with hospital waiting times since the Covid-19 pandemic. While the backlog is slowly easing, waiting times remain considerably longer than they were before March 2020, a problem exacerbated by staffing shortages across Wales. As a snapshot, the statistics for December 2023 show that there were 756,333 open patient pathways in Wales, of which 328,892 had been waiting at least 26 weeks for treatment.¹⁷ Of these, 240,764 had been waiting at least 36 weeks. Particular areas that are experiencing long waits include general surgery, dermatology, ophthalmology, urology, gynaecology, orthopaedics and ear, nose and throat.¹⁸ While statistics vary across health boards, the fact remains that recovery has been sluggish: as of August 2023, there were still over 27,000 patient pathways that had been awaiting treatment for more than 2 years.¹⁹

Long-term waits for treatment pose many risks to patients, particularly older patients. Naturally, the longer an individual waits for treatment, the greater the risk that their health condition will worsen. This brings with it the risk of the patient developing further conditions as a result, such as an untreated knee injury causing damage to the other leg due to the need to compensate for the knee's inability to carry weight.

¹⁵ RCEM Wales (2023), *Wales' Emergency Medicine Workforce: Census 2023*.

¹⁶ Welsh Government (January 2023), 'Advanced Paramedics reducing hospital admissions'.

¹⁷ StatsWales (December 2023), 'Patient pathways waiting to start treatment by month, grouped weeks and stage of pathway', <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Referral-to-Treatment/patientpathwayswaitingtostarttreatment-by-month-groupedweeks>.

¹⁸ Senedd Research (November 2023), *NHS Wales Waiting times – termly monitoring report*, <https://business.senedd.wales/documents/s500010119/NHS%20waiting%20times%20-%20monitoring%20report%20November%202023.pdf>.

¹⁹ *Ibid.*

Older people have likewise complained that NHS services do not maintain clear lines of communication with patients while they wait for treatment, meaning that many are unaware of how to manage their symptoms while waiting, how to report changes in their symptoms, and how to use the non-standardised NHS appointment booking systems.²⁰ Furthermore, lengthy waits for treatment by NHS services are increasingly pushing older people (or rather those who can pay) to arrange for private treatment.²¹ (it is worth noting that, in an Independent Age survey run in 2021, only 20% of people considered private healthcare affordable).²² This represents a failure by the NHS to meet the care needs of the population, and also widens the gap in health and wellbeing between those of different socio-economic backgrounds.

We believe that reducing waiting times for treatment across all departments must be a priority for the NHS in Wales. However, this cannot come at the cost of care quality, which must be maintained to rigorous standards. Where a lengthy wait is inevitable (i.e., more than 6 months), health services must ensure that patients receive a personalised care and management plan for their waiting time, and should collaborate with local authority services and the third sector to provide personalised support for those waiting for treatment.²³ This is important as it may stop the patient's condition from deteriorating during the waiting period, meaning that they are still fit for surgery when it becomes available. Lastly, the NHS must ensure that patients are kept in close communication with health services throughout their waiting time, informing them of where they can access support and what measures they can take to manage their symptoms.

In-patient experience

As discussed earlier in this statement (see 'Dignified Care'), it is important that the principles of dignified care are maintained throughout healthcare settings.

Unfortunately, the lack of research into in-patient experience in NHS hospitals in Wales since the Covid-19 pandemic makes it difficult to offer a comprehensive picture of how well hospitals are maintaining dignity of care. One (published) exception is the unannounced inspection of the Emergency Unit and Assessment Unit at the University Hospital of Wales (also known as the Heath Hospital) in Cardiff, which took place in summer 2022.²⁴ This inspection found that, while most patients praised the efforts of hospital staff, there were some considerable cases in which the dignity of patients was not fully respected. Examples included the inadequate provision of water, food and toilets, a lack of seating space resulting in

²⁰ Independent Age (2021), *Patiently waiting: Older people's experiences of waiting for surgery*.

²¹ Age Cymru (2023), *What matters to you? – Current experiences of people aged 50 and over in Wales*.

²² Independent Age (2021), *Patiently waiting: Older people's experiences of waiting for surgery*.

²³ Independent Age (2021), *Patiently waiting: Older people's experiences of waiting for surgery*.

²⁴ Healthcare Inspectorate Wales (September 2022), *HIW Hospital Inspection Report (Unannounced): Emergency Unit and Assessment Unit, University Hospital of Wales, Cardiff and Vale University Health Board*, [NHS Hospital Inspections 22-23 - UHW - Inspection Report Full - 2022-06-20 FINAL.pdf \(hiw.org.uk\)](https://hiw.org.uk/nhs-hospital-inspections-22-23-uhw-inspection-report-full-2022-06-20-final.pdf).

people sitting on bins while awaiting treatment, and the carrying out of minor surgical procedures (e.g., removing a cannula) in full public view.

There are many standards that should be adhered to in order to provide dignified treatment in NHS hospitals, many of which fall under the duties of candour and quality, as set out in the Health and Social Care (Quality and Engagement) (Wales) Act 2020.²⁵ Some fundamental standards that should be enforced across all hospitals in Wales include ready access to water, food and accessible toilets (this includes giving patients freedom to use the toilet whenever they like, rather than forcing them to go at certain times), adequate bed and seating space for patients, continence care, basic privacy for medical procedures, and respectful communication with patients. Patients should also be supplied with adequate information on the treatment they are experiencing, so that they can make informed decisions regarding any medical procedures.

The Welsh Government and NHS Wales must also ensure that more research is carried out into the state of dignified care in hospitals across Wales, and how this has changed in the years following the pandemic.

Appropriate hospital discharge

In recent years, Age Cymru has received a growing number of reports of patients – particularly older patients – experiencing inadequate hospital discharge procedures, with individuals being rushed out of hospital without the appropriate consideration of their care needs, or of the accessibility of follow-on care. This may be due to growing pressures on hospitals to free up bed space and staff for new patients, but it remains a serious problem that can have a harmful effect on patients if managed poorly. Furthermore, people who have been discharged without the appropriate considerations may well find that their health conditions return, resulting in them returning to hospital to deal with the same issue.

A key aspect of this rushed approach to hospital discharge is the lack of consideration given to the wider needs of patients. Discussions held by Age Cymru with older people show that, across multiple health boards in Wales, patients are being discharged once medically fit without considering their external social conditions (e.g., whether their home is accessible, the availability of care in their local area, distance from GP surgery or pharmacy).²⁶ Poor communication is likewise an issue.²⁷ In some cases, individuals were discharged without their family members being given time to organise follow-on care – a particular problem if the patient lives alone, or with a relative who also has care needs. Others have also been discharged without the appropriate medical aids or care package being allocated to them, as well as a lack of guidance on medication.

²⁵ Welsh Government (2023), 'Written Statement: Commencement of the Health and Social Care (Quality and Engagement) (Wales) Act 2020'.

²⁶ Many of these examples are drawn from interviews with older people who had experienced issues with hospital discharge undertaken by Age Cymru over 2023-24.

²⁷ British Red Cross (2022), *Listening to what matters: Placing people's needs at the centre of hospital discharge practice and policy in Wales*.

At the same time, there have been cases of hospitals discharging patients into care settings without having the appropriate discussions with the care practitioners first. This includes hospital staff not checking whether care homes have the capacity to meet the needs of an individual being discharged. We have also noted rising cases of 'reluctant discharge', in which hospitals move an individual against their will to an external (and theoretically temporary) care setting in order to free up bed space. There is, however, no guarantee that the individual will leave this new care setting, and it is possible that they may return to the hospital if their condition worsens.

The flip side is that many older people are also 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 have heard 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 most of the older people they speak to do not know that there even *is* a discharge planning process, let alone that they have a right to be involved in it from the point of admission.

Ensuring safe and considerate hospital discharge is a priority for NHS hospital services going forward. When preparing a patient for discharge, hospitals must ensure that comprehensive checks are undertaken to make sure that the patient will continue to receive adequate follow-on care, and that their home environment is suitable to their continuing care needs. Hospitals should also check an individual's transport needs, to avoid cases of patients being discharged and then being unable to easily return home. In cases where an individual is discharged to a care home, the hospital must check that the home has the capacity and skills required to care for that person. This must all be done in good time, to avoid a patient having to stay longer in hospital than necessary.

All patients should be supplied with adequate information on their continuing care needs upon leaving hospital, and a clear line of communication should be maintained between health professionals and the former patient. Hospital pharmacies should also ensure that patients have timely access to prescriptions required to enable discharge.

Lastly, it is important that patients are made aware of the discharge planning process and their right to be involved in the process from the point of admission.

Key calls:

- Plans must continue with reforming the health and social care services with the long-term aim of limiting hospital use to acute healthcare needs, rather than as a catch-all for any health problems. Among other things, this will mean ensuring that adequate and well-funded preventative services are in place in communities across Wales.
- Factors that could help to reduce unscheduled hospital admissions should be strengthened, including increasing public awareness of the NHS 111 line and driving forward the rollout of Advanced Paramedic Practitioners (APPs) across Wales.

- The reduction of post-pandemic hospital waiting times should be prioritised, but not at the cost of quality of care.
- For waiting times of 6 months and over, health services must ensure that patients receive a personalised care and management plan for their waiting time, and should collaborate with local authority services and the third sector to provide personalised support for those waiting for treatment.
- Patients must be kept in close communication with health services while waiting for hospital treatment, informing them of where they can access support and what measures they can take to manage their symptoms.
- Fundamental standards of dignity should be enforced across all hospitals, including ready access to water, food and toilet facilities, adequate bed and seating space for patients, continence care, basic privacy for medical procedures, and respectful communication with patients.
- Patients should be supplied with adequate information on the treatment they are experiencing, so that they can make informed decisions regarding any medical procedures.
- Hospital discharge should take place in a safe, timely and appropriate manner. The discharge process should account for the personal and social circumstances of patients, as well as medical. Hospitals should maintain a clear line of communication with patients following discharge.
- Patients must be made aware in advance of the hospital discharge planning process and their right to be involved in the process from the point of admission.
- The Welsh Government should undertake an audit of hospital-to-home services to ensure the continued availability and accessibility of these services across all health boards.

Hospital Transport

Most older people in Wales live beyond walking distance from their nearest hospital or health centre.²⁸ This is increasingly the case as health services are rationalised and moved to larger sites outside towns and cities. It is therefore vital that older people have access to transport to and from health services, both for the sake of their own health and the smooth running of the services themselves. Sadly, transport to and from hospitals is often inadequate, especially in rural areas. Non-motorised transport methods are similarly poor, with many older people remarking on uneven pavements, poor street lighting and unsafe active travel routes.²⁹ Furthermore, many have complained that health services do not take into account age when planning treatment, resulting in older patients being forced to take long and difficult journeys to access treatment. For example, we heard of one individual in their nineties living alone in Pembrokeshire who had to travel unaccompanied via several bus routes across multiple local authorities to receive surgery.

The NHS will provide Patient Transport Services (PTS) to those who are unable to travel to and from hospital independently (not including emergency cases). The official criteria for use of PTS are:

²⁸ Older People's Commissioner for Wales (2021), *Accessing Health Services in Wales: Transport Issues and Barriers*.

²⁹ *Ibid.*

- those whose condition means they need additional medical support during their journey;
- those who find it difficult to walk;
- parents or guardians of children who are being transported.³⁰

In practice, however, the availability and criteria for accessing PTS vary widely across different health boards. Information on PTS is not always up-to-date or available in an offline format (and, in some cases, even the online information is missing or incorrect). Concerns have also been raised that, if circumstances change, individuals are expected to cancel PTS in advance – something that may put people off booking it in the first place.

Some areas in Wales offer community transport solutions, such as the Fflecsi Bwcabus scheme that operated across West Wales until its funding was withdrawn in autumn 2023.³¹ While these can help older people access health services more easily, they are heavily dependent on continued funding from Welsh Government, which is often not sustained over a long period of time.

Many older people equally rely on public transport (primarily buses) to access health services. At present, bus services are experiencing cuts to routes and times across all local authorities in Wales, with rural areas hit hardest.³² Many older people also struggle to access updated bus timetables which they assume are only available online (in fact, all public bus timetables can be accessed via the Traveline Cymru phone service, but public awareness of this service is limited).³³ Age Cymru has also heard of continued issues around the inaccessibility of bus stops and train stations, as well as the lack of toilets available to users.

In many cases, taxis are filling the gap left by public transport services.³⁴ However, taxis are just as vulnerable to market forces as bus companies: those (mostly rural) areas that have seen cuts to bus services due to unprofitability are likewise seeing a reduction in the availability of taxis, as taxi companies are also unlikely to remain in areas with comparatively few customers.

Private cars are still the most common form of hospital transport, with 60% of older people using a car to access health services.³⁵ However, cars too are an increasingly unreliable form of hospital transport due to rising fuel prices. Furthermore, we have received reports of older people having difficulty parking at hospitals and other health centres, often due to a lack of available parking space.

Hospital transport is a multifaceted issue and addressing it will require intervention across both the public and private sectors, with a particular focus on public transport reform across the country. Of most importance to this policy statement, however, is

³⁰ NHS (May 2023), 'How to organise transport to and from hospital', <https://www.nhs.uk/nhs-services/hospitals/going-into-hospital/how-to-organise-transport-to-and-from-hospital/>.

³¹ Dafydd Morgan, 'Fflecsi Bwcabus: Concerns over the end of 'lifeline' bus service', *BBC News*, 26 September 2023, <https://www.bbc.co.uk/news/uk-wales-66919850>.

³² Age Cymru (2023), *What matters to you? – Current experiences of people aged 50 and over in Wales*.

³³ Older People's Commissioner for Wales (2021), *Accessing Health Services in Wales: Transport Issues and Barriers*.

³⁴ *Ibid.*

³⁵ *Ibid.*

that PTS is equally available across all health boards, with broad criteria for access and reliable, regularly updated information available both online and via offline channels. At the same time, Welsh Government should allocate sustainable funding streams to community transport schemes, especially in rural areas. Lastly, hospitals and other health centres must ensure the adequate provision of parking spaces, including dedicated accessible spaces.

Key calls:

- The Welsh Government must support public transport networks across Wales, to ensure regular bus and train services – including in more rural areas. Public transport must also be easily accessible to users, and transport timetables and other information must be available via both online and offline sources.
- Patient Transport Services (PTS) should be guaranteed across all health boards in Wales, with broad criteria to maximise availability of use. This should be complemented by clear, accessible and up-to-date public information on PTS.
- The Welsh Government should allocate sustainable funding to community transport initiatives (e.g., the Dormant Assets fund) to ensure their continued operation in the long term.
- All hospitals and other health centres must have adequate parking facilities, including accessible parking spaces.

GP Services

For most older people, an appointment with the General Practitioner (GP) remains the first port of call for health complaints. While the pandemic has changed the way that many GPs offer appointments, with many opting for a telephone appointment as default unless the individual requests otherwise, older people are nonetheless reliant on GP surgeries for advice, writing prescriptions, resolving minor health conditions and referrals to more specialist treatment.³⁶

The population as a whole remains relatively content with the services offered by GP surgeries in Wales, with 86% of respondents to the 2021-22 National Survey for Wales stating that they were satisfied with the care they received from their GP.³⁷

However, we have noted a growing dissatisfaction among older people with the aspects of the services offered by GP surgeries in Wales. In Age Cymru's 2023 annual survey, 72% of respondents told us they had had a negative experience of accessing GP care in the last 12 months.³⁸ For many, the key problem was the appointment system. For most GP surgeries, appointments are booked via a same-day phone-in system, which can lead to a morning rush as large numbers of people

³⁶ As of 2022, 50% of GP appointments in Wales now take place remotely, whether via phone or video call. Source: Welsh Government (November 2022), 'Hospital and GP services (National Survey for Wales): April 2021 to March 2022', <https://www.gov.wales/hospital-and-gp-services-national-survey-wales-april-2021-march-2022.html>.

³⁷ *Ibid.*

³⁸ Age Cymru (2023), *What matters to you? – Current experiences of people aged 50 and over in Wales*.

call in to secure an appointment for the same day. Many surgeries also use the My Health Online booking system, but this system requires the individual to book their appointment in advance, often by well over a week. Online booking systems are also naturally unavailable to people who do not use the internet, or struggle to do so. Furthermore, booking appointments has become harder across the board as many GP surgeries are limiting their hours due to chronic staff shortages.

We have also heard of a lack of information sharing between staff, as well as between different GP surgeries and more specialised healthcare practitioners, making it harder for an individual to move between different practitioners as their needs require. More alarmingly, some older people have reported to us that their health complaints were not treated seriously by GP surgery staff on account of their age.

Changes to the provision of GP services are underway in Wales. Under the Accelerated Cluster Development (ACD) plan (due to be carried out over the 2020s), the Welsh Government aims to bring together all local health and care services to better coordinate responses to personal and community health.³⁹ This would include bringing together GP surgeries, dentistry, optometry, community pharmacies and other services into a single network – and ideally a single centralised location. The ACD plan has the potential to streamline people's access to various forms of community healthcare by removing multiple administrative (and physical) barriers, making healthcare provision more dynamic and capable of keeping up with increasingly fast-paced changes to healthcare needs.

This plan has great potential, but it must be adequately resourced, clearly communicated and must take into account the needs of older people, such as ensuring that new health clusters are accessible via public transport. It is also important to ensure that some routine services are still available within the community, rather than being entirely removed to centralised locations.

In the meantime, there are other changes that should take place to improve older people's access to GP surgeries. These include developing a more user-friendly and less competitive booking system, that does not disadvantage those who do not use the internet, as well as working to eliminate persisting ageist assumptions around older people's health complaints.

Most importantly, the Welsh Government and NHS in Wales must address the chronic staff shortages and poor staff retention rate across GP surgeries. Without a more sustainable staffing model, GP services will continue to be squeezed, reducing people's access to healthcare and the quality of care offered.

Key calls:

- The Welsh Government and NHS must address chronic staffing shortages in GP surgeries across Wales.
- The Welsh Government should press ahead with the Accelerated Cluster Development plan, while taking into account the needs of older people (e.g.,

³⁹ NHS Wales, 'Accelerated Cluster Development Toolkit', <https://primarycareone.nhs.wales/tools/accelerated-cluster-development-toolkit/>.

transport needs, the need for some routine services to remain in the community) in doing so.

- GP surgeries should reform their appointment booking systems so that people are able to book both same-day and advance appointments without issue. Offline options should be maintained for those who are unable to use the internet (or choose not to).
- GP surgeries must work to eliminate ageist assumptions towards older people and their health complaints.

Community care services

A lot of care for older people is given outside the hospital with community-based services provided by a mixture of social care professionals and 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 medical setting kept as short as is safe to do so. We also believe that care should be personalised, with care packages being built around the needs, routines and preferences of the individual receiving care.

For this reason, we support the move towards integrating social care and health care as a means of providing continuous, coordinated and personalised care for individuals, regardless of whether they are at home or in hospital. To facilitate this approach, we support the development of a National Care Service and would like to see health boards and local authorities working closely together to provide long-term care for older people once they leave a hospital setting.

Unfortunately, social care services in Wales are often not up to the standard required by the older people they serve. Although the pandemic exacerbated matters, the problems with community care in Wales are deep-rooted and can be traced back to before the pandemic. Research by Age UK shows that cuts to local authority budgets and an overreliance on private care providers, who are unevenly spread and fluctuate with market changes, has made it harder for older people to access affordable, consistent care in their local area.⁴⁰ These strains on social care services also make it more difficult to provide personalised, needs-based care, as carers do not have the time and resources to individualise the care process.

Another problem is staffing: the typically poor pay and conditions experienced by many social carers makes the role unattractive to those seeking work. Carers work long hours and are often not appropriately trained for the tasks they are expected to undertake. The pay is usually poor – often lower than a job in healthcare, or even in retail or hospitality – and there is relatively little career structure in place to offer a chance at promotion.

At the same time that community care services are under threat across the country, there is a growing public interest in 'healthcare at home' solutions.⁴¹ In brief, this means standalone therapeutics that can be administered at home, as well as digital devices to help individuals take medication, maintain health behaviours, and even

⁴⁰ Age UK (2023), *Fixing the foundations: Why it's time to rethink how we support older people with health problems to stay well at home*.

⁴¹ PA Consulting (2023), *Healthier at home: Creating value for all in the shift from hospital to home*.

self-diagnose. Healthcare at home is still an emerging field and is being pushed by supporters as a means of freeing up community care staff – as well as reducing reliance on hospital treatment for otherwise preventable health conditions. This may be something that takes on greater importance in future (76% of pharmaceutical and medical technology companies worldwide are shifting to prioritise home-based care products and services), but its potential usefulness as a means of moving society away from relying on community care should be borne in mind going forwards.⁴²

Disease prevention, screening and other community health services are covered in greater detail in Age Cymru's Health Interventions and Preventative Services policy statement.

Key calls:

- Regional Partnership Boards (RPBs) must prioritise the provision of high-quality, consistent at-home care to older people. Care packages should be built around individual needs, routines and preferences, drawing on support from both health and social care as necessary.
- To facilitate this, there should be greater integration of social and health care in Wales. The development of a National Care Service should be used as a means of promoting social care as an equal partner to health care in the provision of long-term care outside of hospital.
- RPBs must tackle staff shortages in social care by addressing the poor pay and conditions experienced by many carers - working as a social carer should not be considered the poor relation of a career in healthcare.
- Consideration should be given to emerging 'healthcare at home' solutions as a means of reducing reliance on community care, as well as a means of avoiding preventable hospital admissions.

Care Homes

Residents in care homes must receive equal access to healthcare, encompassing both physical and mental health. 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, especially when it comes to mental health. Some care homes have a GP allocated to residents or weekly visits from psychiatric staff while others do not. Indeed, mental health services are particularly patchy when it comes to care homes, with the availability of mental health services and staff depending greatly on the area.⁴³

Variable access to healthcare services gives rise to concerns about whether regular reviews of medication are being conducted consistently in care homes across Wales. The Royal Pharmaceutical Society Wales recommends that care home residents receive a medicines review upon entering a care home and a minimum of an annual review thereafter.⁴⁴ (For further information on the risks of inappropriate

⁴² *Ibid.*

⁴³ Age Cymru (2023), *Supporting good mental health of older adults in care homes.*

⁴⁴ Royal Pharmaceutical Society Wales (March 2016): *Improving Medicines Use for Care Home Residents.*

prescriptions, please see the section 'Dementia care (Use of antipsychotic medication)' below).

Lastly, we believe that care homes should represent a continuation of a person's life, albeit in a different setting. As such, care home staff should aim to gain a holistic impression of each new resident at the moment of their transition into the care home, including information on their cultural background, language, relationships, previous work, responsibilities, interests, hobbies, sociability and other factors.⁴⁵ The care home can then use this information to provide a more person-centred care experience – one that minimises the disruption to their life as they move into a care home setting. This is not simply a matter of courtesy, but rather a case of helping care home residents to live a more personally meaningful life, which can ultimately have a positive impact on both their mental and physical health.

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 (including mental health care) when necessary.
- People who live in care homes should have their medicines reviewed annually in order to manage the effects of polypharmacy.
- Care homes should use the transitional process into a home to learn about new residents in a holistic sense. This can help staff to minimise disruptions to the individual's life and create a care package that is more closely built around their personal background, needs and preferences.

Staffing and Workforce

As has been described throughout this statement, health services in Wales cannot continue to operate effectively without adequate numbers of trained staff.

As of December 2023, there were 111,526 people directly employed by the NHS in Wales, as well as an unknown number of contracted workers.⁴⁶ The number of NHS staff has gradually increased over recent years, but there are fears across multiple areas of care that staffing levels are not high enough to cope with the workload faced by the health services, with GP surgeries, emergency care and dentistry among those specific services that have been heavily disrupted by staffing shortages. Some services are filling the gap with agency staff, who tend to be less well-trained, less experienced and short-term in their roles, whereas others are simply struggling along with reduced staff, leading to a mixture of overworked staff (an NHS England survey found that 46.8% of NHS staff felt unwell due to workplace stress), limited services and reduced opening times.⁴⁷ This is particularly the case in rural areas, where there

⁴⁵ For further information, see Age Cymru (2024), *Preserving what matters: integrating mental health into care home transitions*.

⁴⁶ Welsh Government (17 April 2024), 'Staff directly employed by the NHS: at 31 December 2023', <https://www.gov.wales/staff-directly-employed-nhs-wales-31-december-2023-html>.

⁴⁷ NHS (2023), 'NHS Staff Survey: National Results', <https://www.nhsstaffsurveys.com/results/national-results/>.

tend to be fewer people available to fill healthcare roles – especially those requiring competence in the Welsh language.⁴⁸

Furthermore, there is a lack of focus on ageing in education and training for healthcare staff in Wales. With the population of Wales set to age considerably over the next few years (from 866,000 in late 2022 to an estimated 1,015,000, or 31% of the population, in 2031), it is vital that the NHS is able to secure correctly trained staff to care for an older and potentially more infirm future population.⁴⁹

The Welsh Government and its partners have taken some measures to address this shortage. In early 2023, the Welsh Government launched the National Workforce Implementation Plan with the aim of resolving staffing shortages.⁵⁰ The first element of this plan has been to launch a new NHS recruitment drive in late 2023, following the relative success of the 2022 ‘Once for Wales’ pilot, which resulted in around 400 nurses joining the NHS.

Further elements of the Implementation Plan include establishing an ‘All-Wales Collaborative Bank’ to help the NHS address short-term staffing problems and move away from the reliance on unstable agency work, as well as encouraging more volunteers to work in the health and care systems. At the same time, Health Education and Improvement Wales (HEIW) is developing plans to deploy reservists to support regular health workers during moments of extreme pressure, such as rolling out an urgent national vaccination programme as occurred during the pandemic.

Over 2024-25, the Welsh Government will issue further plans for resolving staffing shortages in key sectors such as nursing, dentistry and pharmacy.

Creating a large, well-trained and sustainable workforce is necessary if Wales is to maintain a functioning public health service that embodies the founding principles of the NHS. The Welsh Government must continue to carry out the National Workforce Implementation Plan, in order to drive up recruitment, move away from the unsustainable agency work model, and insulate the NHS against future shocks, as witnessed during the pandemic. Trained volunteers could be better utilised to support patients as part of this initiative, but should never be used to replace qualified staff.

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. Further work is needed to identify appropriate staffing levels and skill mix in community services and care homes in particular. The Welsh Government should also work with HEIW and the education sector more broadly to address gaps in training, such as the current widespread lack of training on ageing in healthcare.⁵¹

⁴⁸ RCEM Wales (2023), *Wales’ Emergency Medicine Workforce: Census 2023*.

⁴⁹ Older People’s Commissioner for Wales (February 2023), *Understanding Wales’ ageing population: key statistics*.

⁵⁰ Welsh Government (January 2023), *National Workforce Implementation Plan: Addressing NHS Wales Workforce Challenges*.

⁵¹ Sally Warren, ‘The health and care workforce’, The King’s Fund (24 November 2022), <https://www.kingsfund.org.uk/insight-and-analysis/long-reads/health-and-care-workforce>.

The Welsh Government and Public Health Wales must explore reforming pay scales and career ladders within the NHS. Working in healthcare is often considered unattractive because there appears to be relatively little opportunity for career advancement, with often little difference in pay between newer staff and their more experienced colleagues.⁵² A payment and career system that more clearly rewarded experience and offered opportunity for promotion may help to incentivise people to work for the NHS and persuade existing workers to stay.

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 key to ensuring that service provision is effective, appropriate and, crucially, person-centred. Greater effort should also be made to support staff who want to learn Welsh and use it in the workplace.

Key calls:

- The Welsh Government must fully implement the National Workforce Implementation Plan to resolve the chronic lack of trained, long-term staff across NHS services in Wales.
- Trained volunteers should be utilised to support patients as part of the Implementation Plan. However, they should never be used to replace qualified staff.
- 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. Further work is needed to identify appropriate staffing levels and skill mix in community services (particularly care homes).
- The Welsh Government should work with HEIW and the education sector to address key gaps in training, such as ageing and the needs of older people.
- The Welsh Government and Public Health Wales must explore ways to reform pay grades and career progression in health services, in order to incentivise people to work (and stay) in healthcare.
- People who speak Welsh as their first language must be accommodated and supported by health and social care services to communicate in Welsh. Greater support should be offered to staff seeking to learn Welsh and use it in the workplace.

Dementia care

Welsh Government dementia strategies

The Welsh Government's Dementia Action Plan 2018-2022 (DAP) set 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.⁵³ Major elements of the DAP included: 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

⁵² *Ibid.*

⁵³ Welsh Government (2018): *Dementia Action Plan for Wales 2018-2022*

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 planned to provide 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 were expected to examine the existing dementia services and care pathways in each area and develop services in line with the DAP that would address these gaps and identify how these services linked up with broader services for the older population. The voluntary sector was expected to play a key role. Progress against delivery of the plan was overseen by a Dementia Oversight, Implementation & Impact Group (DOIIG), including people living with dementia and their carers and families.

The DAP was viewed with general positivity after it came to an end in 2022. Commentators claimed that it 'offered suitable governance and provided a vehicle for partnership and cross-sector working', and it was praised for its focus on placing those with dementia (as well as their relatives and carers) at the centre of dementia care and care planning, via the use of Multi-Disciplinary Teams.⁵⁴ The DAP was successful in making dementia a strategic priority for RPBs, and drove the establishment of new structures (e.g., forums, panels, steering groups) that would help to carry out the improvement of dementia care in Wales.

At the same time, the DAP faced significant barriers to its implementation, including variable health and social care infrastructure across different regions, inconsistent access to services, inequitable provision of care, capacity issues within local health and social care, an overly medical (rather than social) approach to dementia care among RPBs, and the problem of 'strategy fatigue', whereby services struggle to keep up with multiple different strategies. It is also not immediately clear whether the Welsh Government has a follow-up plan in place to continue the work begun by the DAP, other than the DPS (discussed below).

From the DAP has come the Dementia Pathway of Standards (DPS), which was implemented over 2021-23. The DPS was developed in collaboration with people living with dementia, care practitioners and voluntary sector organisations, and consists of 20 standards grouped under 4 themes (Accessible, Responsive, Journey, Partnership & Relationships), themselves linked by the overarching theme of Kindness & Understanding. The DPS is explicitly person-centred in its approach, with each theme being 'wrapped around' the person. It is up to RPBs and Dementia Forum to match relevant organisations with the appropriate standards, and to decide how such organisations can meet these standards.

While we agree with the person-centred approach of both the DAP and the DPS, several aspects of the Welsh Government's current strategic approach to dementia concern us. Firstly, it is unclear how effective the DAP – and subsequent DPS – have been. Both were rolled out in a relatively short space of time, and there has been little research into the success of their implementation. In particular, we would like to see evidence of the effective rollout of the DPS, how organisations will be monitored in order to keep to its standards, and whether RPBs are receiving the

⁵⁴ Improvement Cymru (2021), *All Wales Dementia Care Pathway of Standards*.

necessary resources to achieve this. While cautious of 'strategy fatigue', we would also like to see a follow-up plan to the DAP, to ensure that dementia continues to be embedded in health and social care services as a priority.

Under-diagnosis

It is estimated that more than 46,000 people in Wales are currently living with dementia and this number is expected to increase significantly over the next decade.⁵⁵ Wales has traditionally had a low rate of dementia diagnosis, compared to the rest of the UK, meaning many people living with dementia in Wales have not received a formal diagnosis.⁵⁶ Furthermore, evidence suggests that dementia diagnoses have been slowed further by the knock-on effects of the pandemic on mental health assessment services.⁵⁷ Without this diagnosis, they are denied access to information, support services and potential treatments that could assist them. The lack of a diagnosis also places greater pressure on unpaid carers, who are often unable to access specialist support.

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.

People with dementia and carers have 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.⁵⁸ 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. Across much of Wales, there are also growing waiting lists leading to delays in diagnosis and intervention.

However, there is some hope in the use of technology to improve dementia diagnosis rates. Over 2019-2021, the Aneurin Bevan University Health Board began using FDG-PET scans as part of a pilot project across the Gwent area.⁵⁹ FDG-PET scans provide earlier diagnosis and more accurate diagnosis of specific dementia sub-types. Following the success of this pilot, the Welsh Health Specialised Services Committee is now aiming to scale up FDG-PET scanning to a national level. We support the scaling up of FDG-PET scanning across Wales, which will provide earlier and more accurate diagnoses, allowing patients to receive support earlier and easing pressure on carers.

⁵⁵ Care Policy and Evaluation Centre (November 2019), *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040*.

⁵⁶ Alzheimer's Research UK *Dementia Statistics Hub* available at <https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk/> accessed 05 February 2019.

⁵⁷ Senedd Cymru, Health and Social Care Committee (April 2022): *Waiting well? The impact of the waiting times backlog on the people of Wales*.

⁵⁸ Older People's Commissioner for Wales, 2016

⁵⁹ Royal College of Psychiatrists (September 2021): *Case study: increasing dementia diagnosis rates in Wales*.

Hospital care

Ideally, older people living with dementia should be cared for in a home setting, as living within a familiar, comfortable environment is important to ensuring the mental (and physical) wellbeing of people living with dementia. However, in reality many people living with dementia receive care in hospitals, whether for conditions related to their dementia or for unrelated ailments. It is therefore crucial that hospitals and hospital staff have the appropriate resources and training in place to meet the needs of patients with dementia.

The ability of hospitals to provide effective, meaningful care to patients with dementia varies greatly. While there are many localised examples of excellent dementia care in hospitals in Wales, there have also been many cases in which the challenges of dementia have not been properly addressed. Most notably, the 2018 HASCAS report into the Tawel Fan ward (Glan Clwyd) highlighted shocking cases of abuse and neglect shown towards people living with dementia in a hospital setting.⁶⁰

Outcomes for people with dementia who are admitted to hospital are still 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 even 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.

In April 2022, Public Health Wales, Improvement Cymru and Alzheimer's Society Cymru jointly published the Dementia Friendly Hospital Charter for Wales.⁶¹ The Charter aims to change how hospitals approach caring for patients with dementia, focusing on recognising the personhood of people with dementia, their diversity of experiences and the importance of personal preference. It also places emphasis on

⁶⁰ HASCAS (May 2018), *Independent Investigation into the Care and Treatment Provided on Tawel Fan Ward: a Lessons for Learning Report*.

⁶¹ Public Health Wales, Improvement Cymru and Alzheimer's Society Cymru (April 2022), *Dementia Friendly Hospital Charter for Wales*.

clear communication between hospital services and patients with dementia, as well as with their relatives and carers.

While the 2022 Charter marks an important step towards improving hospital care for patients with dementia, its implementation must be matched by rigorous quality standards that should be monitored by Welsh Government to ensure their maintenance.

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 sector. All health and care staff should also be able to provide appropriate information on dementia and signpost to advice and support services.

Recent years have seen the expansion of dementia awareness and training programmes by organisations including Social Care Wales, HEIW and Cofio.⁶² These training programmes have been aimed at people working in both social and healthcare, as well as unpaid carers.

This is a positive step, but there is always room to expand dementia training further across society in Wales. With the number of older people living with dementia set to increase by 70% in Wales by 2040, it is vital that dementia training is extended to as wide an audience as possible, including those working outside of formal health and social care roles.⁶³

Use of antipsychotic medication

Antipsychotic drugs are a form of medication used to treat patients experiencing 'severe agitation, aggression or distress from psychotic symptoms, such as hallucinations and delusions'.⁶⁴ They are sometimes used to treat people living with dementia, particularly if they are showing persistently aggressive behaviour and there is a risk of harm to either themselves or others.

Antipsychotics should be administered with great care for several reasons. Firstly, they pose a considerable risk to patient health – a risk that increases with dosage and length of prescription. Potential side-effects include drowsiness, memory loss and reduced cognitive ability, increased risk of blood clots and even strokes.⁶⁵ The Royal Pharmaceutical Society argues that antipsychotics increase the risk of death

⁶² Welsh Government (5 April 2022): *Update on dementia care in Wales*.

⁶³ LSE Care Policy and Evaluation Centre (November 2019): *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*.

⁶⁴ Alzheimer's Society (2021), 'Antipsychotics and other drug approaches to dementia care', <https://www.alzheimers.org.uk/about-dementia/treatments/drugs/antipsychotic-drugs>.

⁶⁵ *Ibid*.

through conditions such as pneumonia, cardiac failure and cerebrovascular disorders.⁶⁶ Secondly, antipsychotics have no effect on most other challenging behaviours associated with dementia, such as anxiety, repetitive vocalisations, social withdrawal and loss of inhibitions.⁶⁷

Due to their high risks and limited usefulness, antipsychotic drugs should only ever be prescribed after first trying non-pharmaceutical approaches to challenging behaviour. They should not be routinely prescribed to treat behavioural and psychological symptoms of dementia. Where antipsychotic medication is required, it should be prescribed at the lowest dose for the shortest possible time, with regular review (Alzheimer's Society recommends every 6 weeks) by an appropriately skilled pharmacist working as part of a multidisciplinary team.⁶⁸ Prescriptions should also be made with a full risk assessment, and consideration should be given to including a statutory Independent Mental Capacity Advocate (IMCA) in the decision to prescribe antipsychotics.

Unfortunately, antipsychotics are still used widely within dementia care in Wales. Care Inspectorate Wales reports that around one quarter of care home residents living with dementia are currently being prescribed antipsychotic medication.⁶⁹ Age Cymru research into mental health in care homes undertaken over 2022-23 likewise reported a tendency towards the overprescription of antipsychotics for care home residents living with dementia.⁷⁰ This research found that the overprescription of antipsychotics was often the result of institutional problems, including a lack of psychological training for care home staff, staffing pressures that mean it is easier to administer medication than using time-consuming psychosocial and environmental alternatives to antipsychotics, and ingrained ageist assumptions that older people living with dementia will not respond to non-pharmaceutical dementia treatment.

More generally, we want to see a cultural change in how dementia treatment responds to behaviours that challenge. Many of the behaviours that are treated with antipsychotics come from a position of poor mental health – something that is often (and erroneously) assumed not to affect people living with dementia. A more robust approach to treating the mental health of people living with dementia could reduce the need for pharmaceutical intervention. One example developed by Age Cymru would be to use the transitional process into a care home to learn more about the resident – about their relationships, their responsibilities, their use of language, their sociability and other factors that play an important role in their sense of identity.⁷¹ By learning about these factors and integrating them into an individual's care, it may be possible to minimise the sense of disruption as an individual moves into care, and to create a more person-centred, individualised care environment. This may in turn

⁶⁶ Bernard Murphy, 'Greater risk of death by antipsychotics in dementia patients, research suggests', *The Pharmaceutical Journal* (2015).

⁶⁷ Alzheimer's Society (2021), 'Antipsychotics and other drug approaches to dementia care', <https://www.alzheimers.org.uk/about-dementia/treatments/drugs/antipsychotic-drugs>.

⁶⁸ *Ibid.*

⁶⁹ Care Inspectorate Wales (September 2020), *National review of care homes for people living with dementia*.

⁷⁰ Age Cymru (March 2023), *Supporting good mental health of older adults in care homes*.

⁷¹ Age Cymru (February 2024), *Preserving what matters: integrating mental health into care home transitions*.

improve their mental health in the long run, reducing the need for potentially harmful pharmaceutical intervention.

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 rather than a matter of choice, this is not reflected in the grassroots services available.⁷²

How people affected by dementia are assessed 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. Important details may be lost during the assessment and transition into care, which can affect future care. When the individual arrives at the care setting, the lack of Welsh-speaking staff and opportunities to use the language on a day-to-day basis can seriously harm their mental health, especially if they lose the ability to communicate in English. This also poses a risk to physical health if the person is unable to communicate their needs clearly.

There have been some movements towards integrating the Welsh language into dementia care, especially in care homes. Social Care Wales has, for example, produced resources to help care homes assess the Welsh language abilities of staff and to encourage carers to learn and use Welsh at work.⁷³

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 calls:

- The Welsh Government must review the implementation of the DAP and produce a follow-up dementia plan to continue the process of embedding dementia care as a priority in health and social care services.
- The DPS should continue to be rolled out across health boards, and effective monitoring put in place to ensure that services are meeting standards. RPBs must receive the necessary resources to allow services to meet these standards.

⁷² Welsh Language Commissioner and Alzheimer's Society Cymru (2018), *Welsh Speakers' Dementia Care*.

⁷³ Social Care Wales (February 2024), 'Using Welsh at work', <https://socialcare.wales/resources-guidance/using-welsh-at-work#:~:text=What%20is%20%27More%20than%20just%20words%27%3F%20%E2%80%98More%20than,Welsh%20language%20services%20for%20those%20who%20need%20it.>

- Diagnosis rates for dementia must be improved across Wales. To facilitate this, the Welsh Government should set long-term targets for a significant improvement in early diagnosis rates across all health boards.
- FDG-PET scanning should be scaled up across Wales, in order to provide earlier and more accurate dementia diagnoses, thereby allowing patients to receive support earlier and easing pressure on carers.
- The Welsh Government must ensure that the Dementia Friendly Hospital Charter for Wales is implemented and rigorously enforced across all health boards.
- 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.
- Hospitals, care homes and other care settings should offer non-pharmaceutical approaches to treating challenging behaviours during dementia care. Antipsychotic medication should only be offered as a last resort, and the prescription process should involve an IMCA. Antipsychotic medication use should be short-term and reviewed every 6 weeks.
- 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 in dementia care, 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

‘Palliative care’ refers to care offered to improve the quality of life of an individual after they have been diagnosed a terminal health condition. ‘End of life care’ specifically refers to care offered during the final stage of an individual’s life (usually the final year).

Around 33,000 people die every year in Wales, the majority of whom require some form of palliative or end of life care to help them die in a dignified and supported manner.⁷⁴ The number of deaths is expected to rise over the coming years as the population of Wales ages, meaning that more people will be requiring palliative and end of life care. At the same time, an older population is expected to have more complex health needs. It is therefore vital that Wales has a robust palliative and end of life care system that can treat a growing number of patients with complex health needs.

Wales has traditionally taken a proactive approach to palliative and end of life care, with NHS Wales taking the step of launching its Palliative Care and End of Life Delivery Plan in 2017 (making it one of only two UK nations at the time to have such a plan in place, the other being Scotland).⁷⁵ However, the reality on the ground is that the palliative needs of many people are still not met. There are many reasons for

⁷⁴ Welsh Government (October 2022), ‘Quality statement for palliative and end of life care for Wales’, <https://www.gov.wales/quality-statement-palliative-and-end-life-care-wales-html>.

⁷⁵ NHS Wales (2017), *Palliative and End of Life Care Delivery Plan*.

this, though a commonly reported issue is that NHS staffing shortages (particularly of GPs and Community and District Nurses) results in people missing out on palliative care that could be delivered at home or in the community. 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.

The Welsh Government has agreed to use the National Institute of Health and Care Excellence (NICE) quality guidelines across all aspects of health and social care, including palliative and end of life care.⁷⁶ The NICE End of Life Care quality standard (2021) lists several key standards that should be applied to treatment for people approaching the end of their lives (which are equally applicable to longer-term palliative care).⁷⁷ These standards include:

- Adults who are likely to be approaching the end of their life are identified using a systematic approach.
- Adults approaching the end of their life have opportunities to discuss advance care planning.
- Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations.
- Adults approaching the end of their life and their carers have access to support 24 hours a day, 7 days a week.
- Carers providing end of life care to people at home are supported to access local services that can provide assistance.

We believe that 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.

We support the Welsh Government's decision to adhere to the NICE End of Life Care quality standard, and want to see these standards implemented and monitored across end of life care and palliative care more generally across Wales. We also want to see an expansion of palliative care services across Wales, to match the needs of an older and more infirm population.

Do Not Attempt Resuscitation (DNAR) orders

DNAR orders are issued when an individual is either unable or unwilling to receive cardiopulmonary resuscitation (CPR) in the event of heart failure, or if their breathing

⁷⁶ National Institute for Health and Care Excellence (NICE) (January 2022), 'National Institute for Health and Care Excellence (NICE) guidelines', <https://www.gov.wales/national-institute-health-and-care-excellence-nice-guidelines>.

⁷⁷ National Institute for Health and Care Excellence (NICE) (October 2019), 'End of life care for adults: service delivery', <https://www.nice.org.uk/guidance/ng142>.

stops.⁷⁸ DNARs can be issued by a doctor (for example, if they believe that CPR poses a serious risk to the individual) or can be chosen by the patient themselves.

There has been some concern in recent years that DNARs were being applied inappropriately across the healthcare system during the Covid-19 pandemic. A UK Government inquiry subsequently found these concerns to be well founded, revealing that DNARs had in many cases been issued on a blanket basis to any older person in care who had contracted Covid.⁷⁹ The inquiry also raised questions around consent and DNARs, as many older patients were found to be unaware that a DNAR had been issued in their name. Others did not know what a DNAR was.

In no circumstances should a DNAR order to be placed on a person's medical records without their knowledge or consultation, either with themselves or with an appropriate family member or advocate. 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.

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. This includes preparing the health and social care services for the higher demand for complex palliative care that is likely to emerge in the coming years.
- The Welsh Government should continue to pursue a proactive approach to palliative and end of life care. It should work to implement the NICE End of Life Care quality standard across health and social care services and monitor their uptake.
- Do Not Attempt Resuscitation (DNAR) orders must not be placed on a person's medical records unless they and/or their family/carer are aware and have been consulted. This also applies to the withdrawal of food and water.

⁷⁸ NHS (December 2023), 'Do not attempt cardiopulmonary resuscitation (DNACPR) decisions', <https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>

⁷⁹ Care Quality Commission (November 2020), *Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic*.

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