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AT BREAKING POINT

Time to transform end of life care in Wales

March 2025

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End of life care is at breaking point

We don't talk enough about death and dying. Despite it touching all our lives, we avoid talking about it. As a result, we often avoid talking about the care and support people need at the end of their lives.

Palliative and end of life care is a critical part of our health and social care system. When we get it right, it can have a profound impact on people living with a terminal illness, and those close to them.

But end of life care is at breaking point. Gaps in provision and a system under severe pressure means too many people are left without the care and support they need.

Demand for palliative and end of life care is growing. By the 2040s, 37,000 people in Wales will likely need palliative and end of life care each year.[1] If our system can't cope now, it stands little chance of meeting future need.

Palliative and end of life care is delivered by a complex mix of generalist and specialist services across the health and social care system. Everyone involved in its delivery must recognise the urgent need for change.

Clear leadership from the incoming Welsh Government will be essential if we are to address the challenges our palliative and end of life care system face. Where Welsh Ministers can directly affect change, they must do so, while holding all parts of our health and social care system to account.

We can't afford to waste time getting this right. People living with a terminal illness and those close to them deserve better. That's why our challenge to policymakers, health boards and providers, including ourselves, is clear: take the radical action needed to truly transform palliative and end of life care.

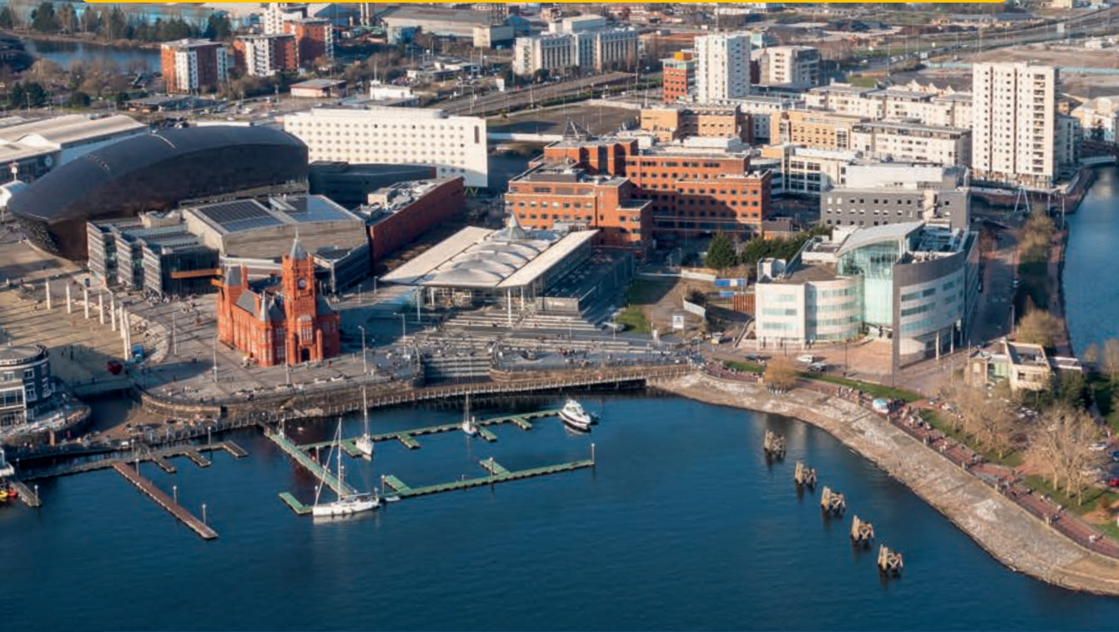
Closing the implementation gap

Wales has an emerging policy framework for palliative and end of life care.

- The **quality statement**[2] sets out a clear destination that government, health boards and providers should be working towards.
- The forthcoming **service specification** has the potential to act as an implementation plan.
- The development of a **commissioning framework** should help achieve greater consistency in service delivery across all parts of Wales.

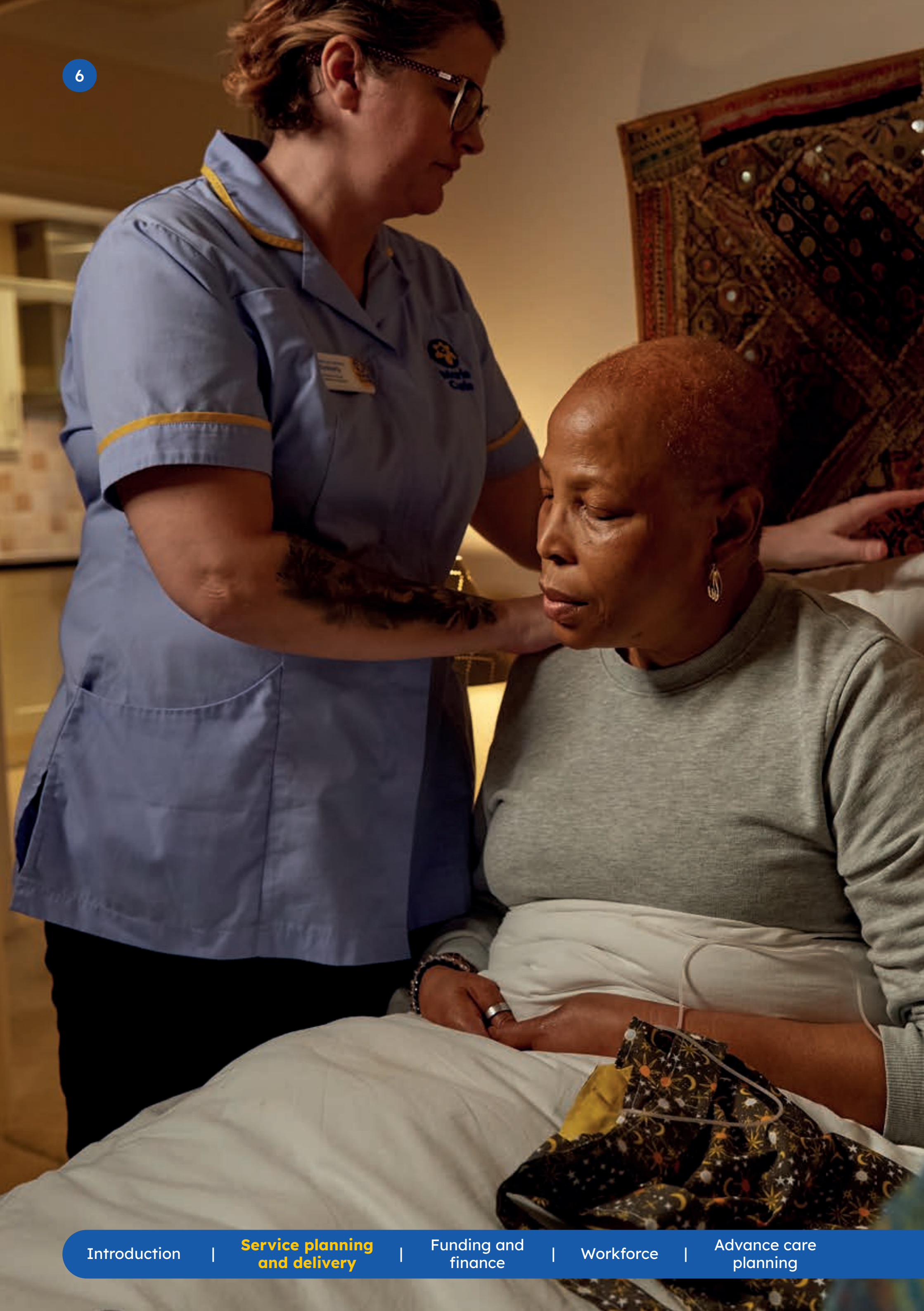
But there is currently a gap between ambition and delivery. We need to close this implementation gap by taking action throughout the palliative and end of life care system.

This manifesto sets out a programme of change which, if coupled with strong leadership and a robust policy and monitoring framework, can ensure that everyone in Wales has access to the palliative and end of life care they need, when they need it.



Actions for the next Welsh Government

1. Ensure palliative and end of life care services are responsive to people’s needs. High-quality care must be available in the right place and at the right time, in all parts of Wales.
2. Sustainably fund palliative and end of life care services to meet the needs of all people living with a terminal illness across Wales.
3. Develop a palliative and end of life workforce that meets the growing need for care. Provide all health and social care professionals with foundational knowledge of palliative and end of life care.
4. Ensure people living with a terminal illness are made aware that their diagnosis could lead to their death. They must be supported to have conversations about their care preferences and to put advance care plans in place.
5. Provide people living with a terminal illness and those close to them, including family and carers, with 24/7 access to care and support.
6. Ensure that people living with a terminal illness are discharged from hospital swiftly, once deemed able to return home. Appropriate support must be in place at the point of discharge, including support to die in their preferred place.
7. Enable everyone in Wales to access the same quality of palliative and end of life care, regardless of who they are or where they live.
8. Regularly assess and review unpaid carers’ needs so they can be provided with the support that they need.
9. Protect people living with a terminal illness from financial insecurity and poverty.



1. Service planning and delivery

The difference that high-quality palliative and end of life care can make for people living with a terminal illness and those close to them, including family and carers, can't be understated. The right care and support enables people to feel protected, safe, and have their wishes and care preferences heard and respected.

Too many people in Wales can't access the care they need. Our health and social care system continues to be shaped by and recreate inequity, while a postcode lottery persists.

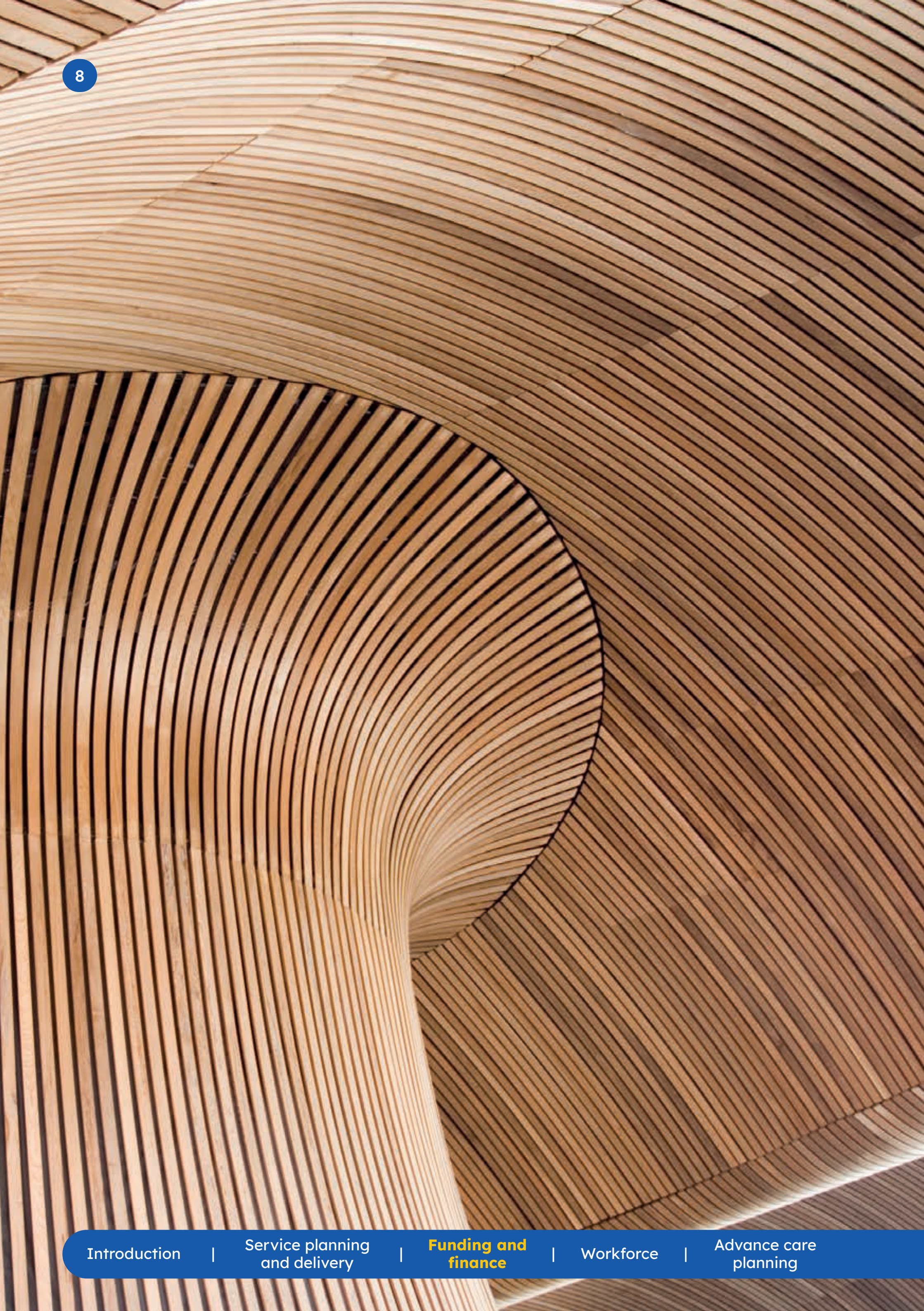
Health boards and local authorities plan and deliver health and social care services. By law, these institutions are required to work together to assess the care and support needs of their local population, whether these needs are being met, and the range and level of services needed. But too often, these assessments fail to consider palliative and end of life care.

Without robust and regular assessments of palliative and end of life care needs, health boards, local authorities and other sector partners lack critical information to understand the level and nature of support required.

Ensure palliative and end of life care services are responsive to people's needs. High-quality care must be available in the right place and at the right time, in all parts of Wales.

Actions

1. Require health boards and trusts to periodically assess palliative and end of life care needs for their local population and use this to inform service planning and delivery. Assessments should be published publicly.
2. Require health boards to publish local delivery plans for palliative care. These should set out how they meet their population's needs and achieve the ambitions set out in the Welsh Government's quality statement.
3. Regional Partnership Boards must include a palliative and end of life care lead to provide expert advice and guidance on meeting the needs of people living with a terminal illness and those close to them.



2. Funding and finance

The Welsh Government have set out clear ambitions for palliative and end of life care in the quality statement. However, current funding and finance models are not sufficient to turn these ambitions into a reality.

Third sector providers of palliative and end of life care are increasingly reliant upon charitable income to deliver services. This is unsustainable, particularly with a growing demand for palliative and end of life care.

Contracting arrangements with health boards often omit funding uplifts, leaving charitable hospice providers under significant strain from increases to National Insurance, Agenda for Change pay, energy costs and broader inflationary pressures. These substantial financial headwinds are leading to significant deficits and cuts to services. In 2024-25, Welsh hospices forecast a collective £9.5 million deficit.[3]

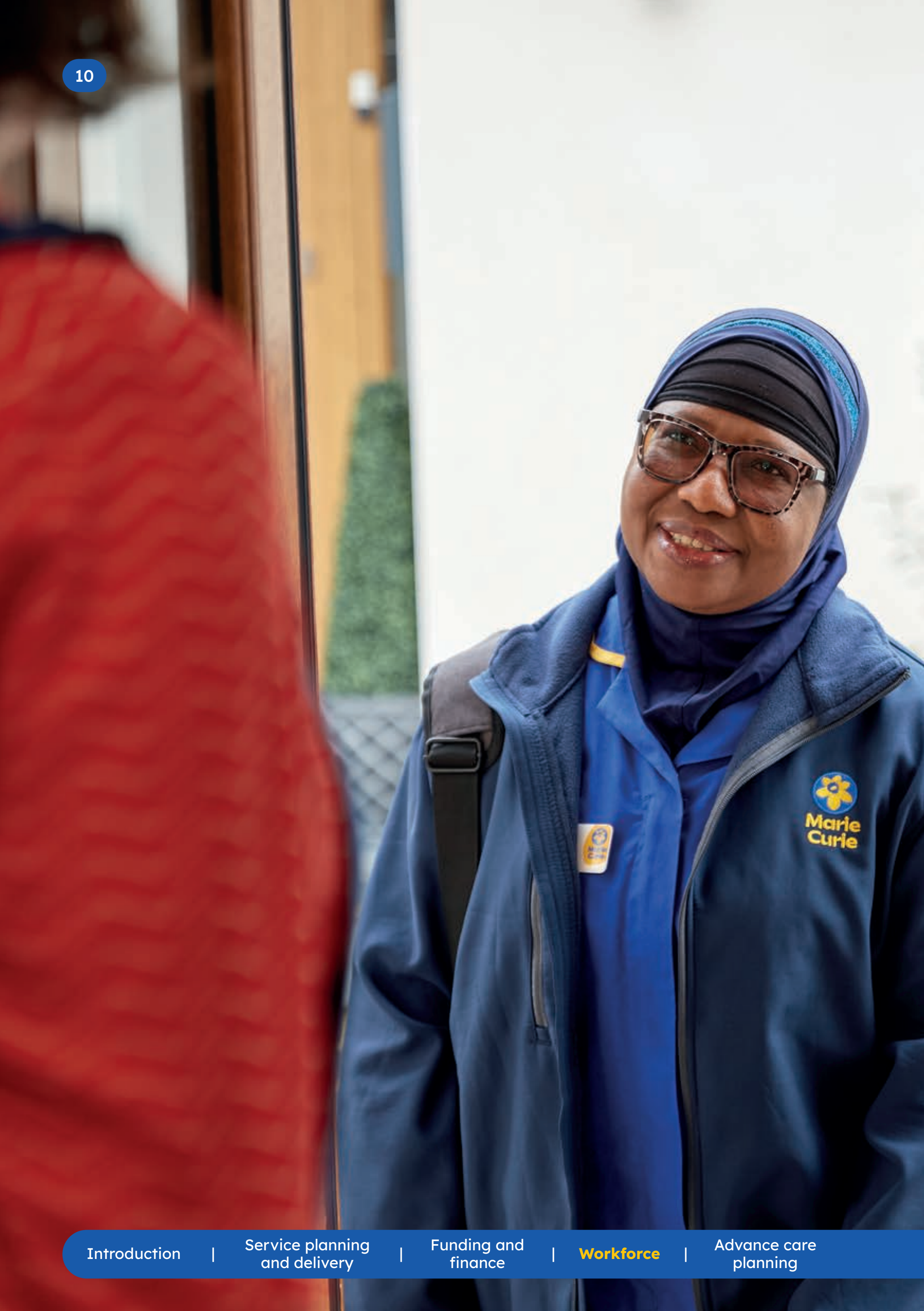
We must move quickly to a sustainable model of funding that recognises the vital role of charities in delivering end of life care services on behalf of the Welsh NHS.

It's essential to develop a new approach to commissioning in order to meet the needs of people living with a terminal illness now and in the future, and to develop new, innovative models of delivery.

Sustainably fund palliative and end of life care services to meet the needs of all people living with a terminal illness across Wales.

Actions

1. Establish a sustainable funding solution to ensure that the palliative and end of life care system can meet the growing need for care.
2. The Welsh Government must commit to funding Agenda for Change uplifts for all palliative and end of life service delivery, while requiring health boards to pass financial uplifts onto third sector providers.
3. The forthcoming commissioning framework for palliative and end of life care must support consistent service delivery and include standardisation of unit price, contract length and terms and commitments to Agenda for Change salary levels.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3. Workforce

Palliative and end of life care is delivered across Wales by a dedicated and compassionate workforce, who operate within specialist services and the wider health and social care system. However, we currently lack a clear and accurate picture of this workforce, hindering service delivery and workforce planning and development.

Additionally, the lack of a palliative and end of life care core competency framework risks leaving health and social care workers without the skills and knowledge they need to effectively support people living with a terminal illness.

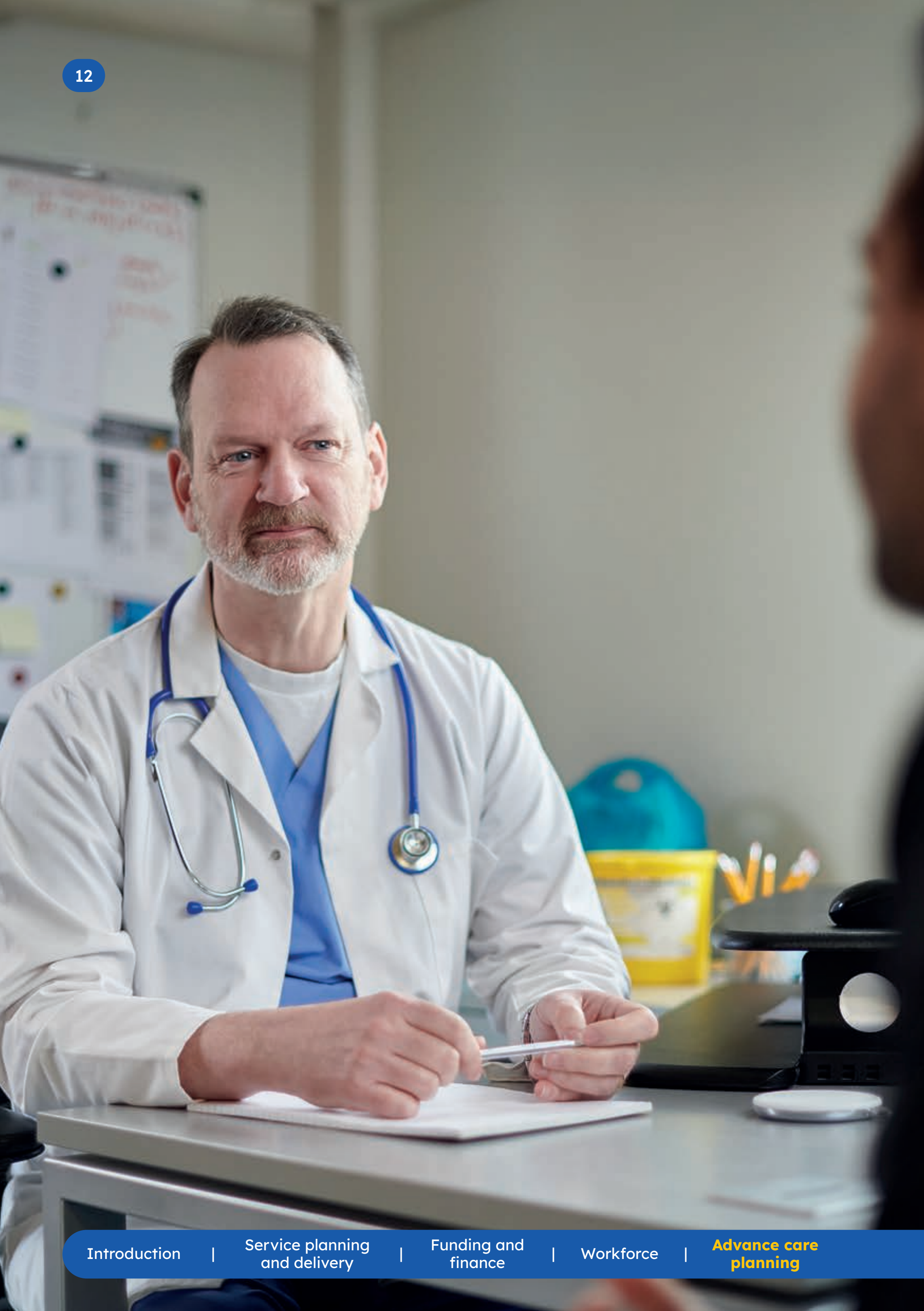
Recruitment and retention issues are placing further pressures on the system, while failing to pass on Agenda for Change uplifts to third sector providers worsen an already challenging situation.

Much of the care and support that people living with a terminal illness need, can and should be delivered in the community, helping people stay closer to home at the end of life, while preventing avoidable hospital visits. To do this, health and social care services need to coordinate effectively and recognise people's distinct and unique end of life care needs.

Develop a palliative and end of life workforce that meets the growing need for care. Provide all health and social care professionals with foundational knowledge of palliative and end of life care.

Actions

1. The NHS Wales Executive and Health Education and Improvement Wales (HEIW) should conduct a regular census of the palliative and end of life care workforce, including the vacancy rate, to aid workforce planning and development.
2. In conjunction with the NHS Wales Executive, HEIW must publish a palliative and end of life care workforce plan based on projections of current and future demand.
3. The forthcoming palliative and end of life care core competency framework must provide all health and social care professionals with the foundational knowledge and skills required to care for people living with a terminal illness, as well as strengthen the skills of the specialist palliative care workforce.
4. Each primary care cluster must have a palliative and end of life care nurse in place to provide expert advice and guidance, and support effective coordination of palliative and end of life care.



4. Advance care planning

Advance care planning enables people living with a terminal illness to have conversations with their healthcare team to make decisions about the care they would like in the future.

Research suggests that conversations about death and dying between people living with a terminal illness and healthcare professionals aren't happening consistently. 25% of people in Wales didn't know that they might die because of their illness, and 37% of bereaved people reported that healthcare professionals hadn't discussed death and dying with the person who died.[4] In this context, it's hard to see how advance care planning discussions can be taking place.

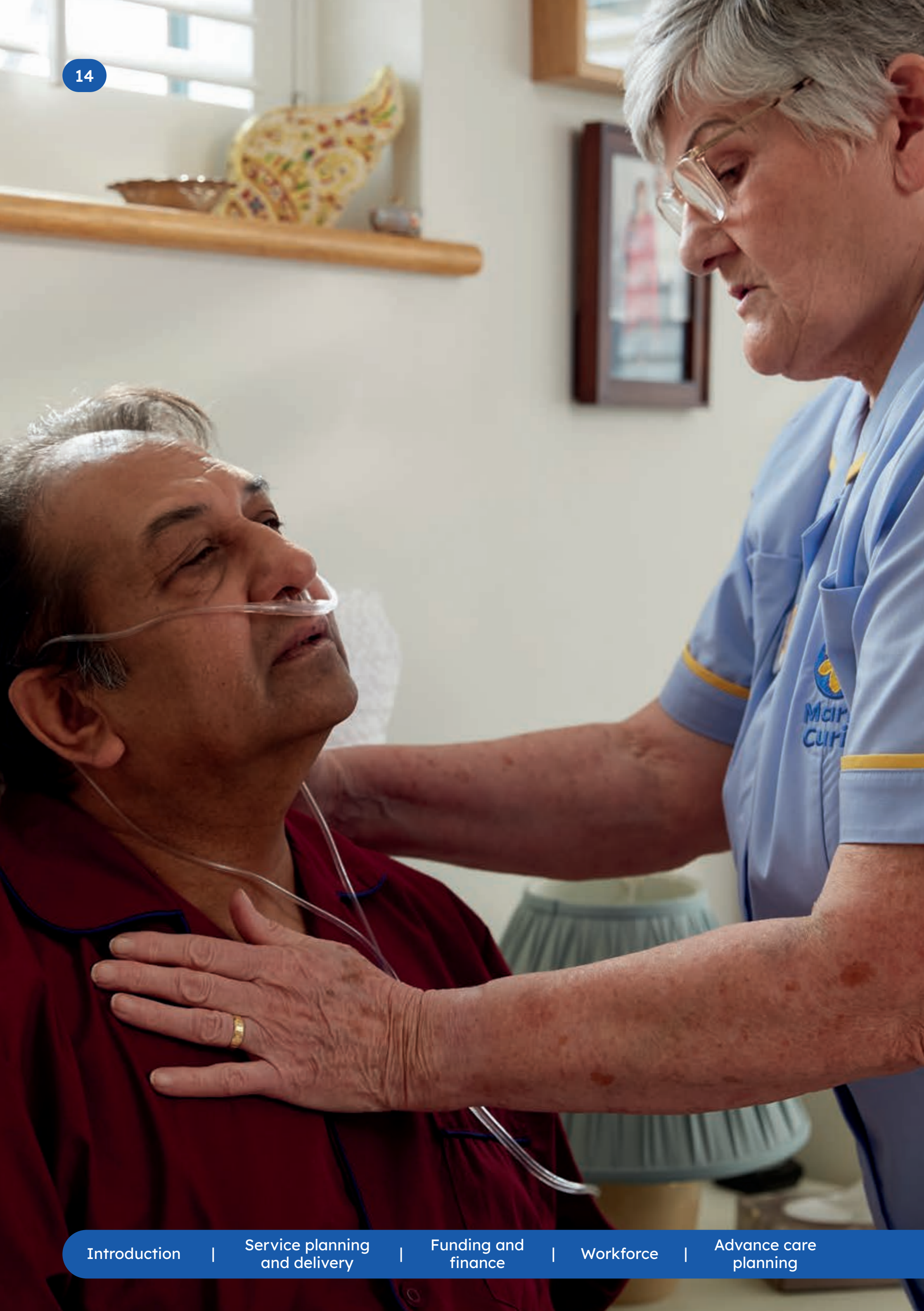
Even when advance care plans are in place, they aren't always accessible to all medical professionals involved in the care of people living with a terminal illness. Instead, many rely on informal schemes such as the Message in a Bottle scheme[5], meaning that too often people must repeatedly articulate their care plans or rely on family members to convey their wishes.

Effective advance care planning is essential to help people living with a terminal illness die in their preferred place, with their wishes understood and respected.

Ensure people living with a terminal illness are made aware that their diagnosis could lead to their death. They must be supported to have conversations about their care preferences and to put advance care plans in place.

Actions

1. Healthcare professionals must properly identify people with a palliative and end of life care need, add them to the palliative care register and refer them to the Specialist Palliative Care service where appropriate.
2. All health and social care professionals must receive advance care planning training.
3. Advance care plans must be included in the All Wales Digital Patient Record and be accessible to all health and care professionals including paramedics.



5. Out-of-hours and community care

Enabling people to die at home, if this is their preference, is a core tenet of good end of life care – and can significantly reduce pressures on urgent and emergency care services. However, gaps in 24/7 community care are preventing people living with a terminal illness from remaining at, or close to, home. People must have access to advice, support, medication and healthcare professionals when they need them.

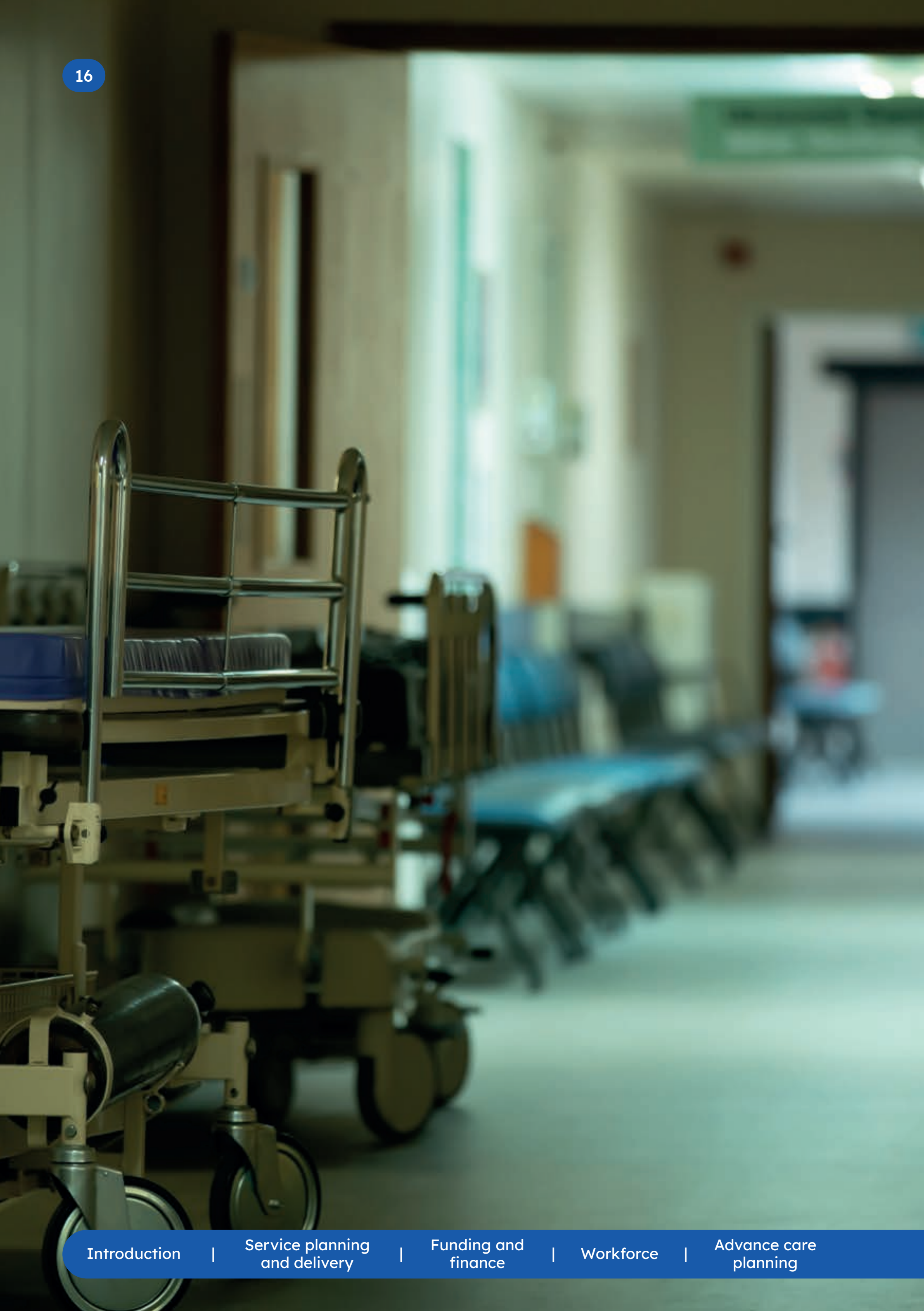
Almost one in five people in Wales had no contact with a GP either in person or over the phone in their final three months of life.[6] In the same timeframe, 48% used an ambulance and 45% visited an A&E department.[7] Of every emergency department attendance in Wales, one in 14 is related to someone in the last year of life.[8]

To enable people living with a terminal illness to remain at home where possible and to reduce avoidable emergency admissions, people must be able to access care and support 24/7, wherever they live in Wales.

Provide people living with a terminal illness and those close to them, including family and carers, with 24/7 access to care and support.

Actions

1. Establish 7-day community and district nursing in all parts of Wales.
2. ‘111 press zero’ must provide a 24/7 single point of access for advice and information, staffed by clinically trained palliative and end of life care staff.
3. Integrate advanced practice palliative care paramedics into core specialist palliative care.
4. Commission community pharmacies to provide a standardised set of palliative care medications and make them available 24/7.
5. Review the commissioning and prescribing of Just in Case packs and address any gaps in access.



6. Hospital discharge

Too many people are in hospital despite being ready to return home or move onto the next phase of their care. On average, in 2024, 1,578 people were in hospital when they didn't need to be,[9] a significant number of whom are likely to have palliative and end of life care needs.

The most common reasons for a delayed transfer of care are assessment issues, accounting for 39% of delays in December 2024..[10] Of these, the most common issue was a delay in social care assessment.[11]

Capacity in the social care sector is a significant issue, impacting people beyond those with palliative and end of life care needs. A well-functioning and well-funded social care system is essential for equitable and high-quality palliative and end of life care, as well as for supporting people living with a terminal illness to return home following a hospital stay.

People living with a terminal illness will often have distinct needs which must inform and shape discharge plans. An inconsistent and poorly-coordinated discharge process for people living with a terminal illness risks further exacerbating delays in transfer of care. Current hospital discharge guidance has little detail on how people living with a terminal illness should be supported to return home.

Ensure that people living with a terminal illness are discharged from hospital swiftly, once deemed able to return home. Appropriate support must be in place at the point of discharge, including support to die in their preferred place.

Actions

1. Hospital discharge guidance must set out how people with a terminal illness should be supported to return home once they can, or if they have indicated that home is their preferred place to die.
2. Discharge liaison teams must be in place in all hospitals, 7 days a week, and should undergo palliative and end of life care and carer awareness training.
3. Delayed Transfer of Care data must be disaggregated by medical condition and palliative care status.

7. Inequity

Inequity continues to heavily shape our day-to-day lives. Biases and discrimination can have a significant impact on people's access to and experiences of palliative and end of life care and support.

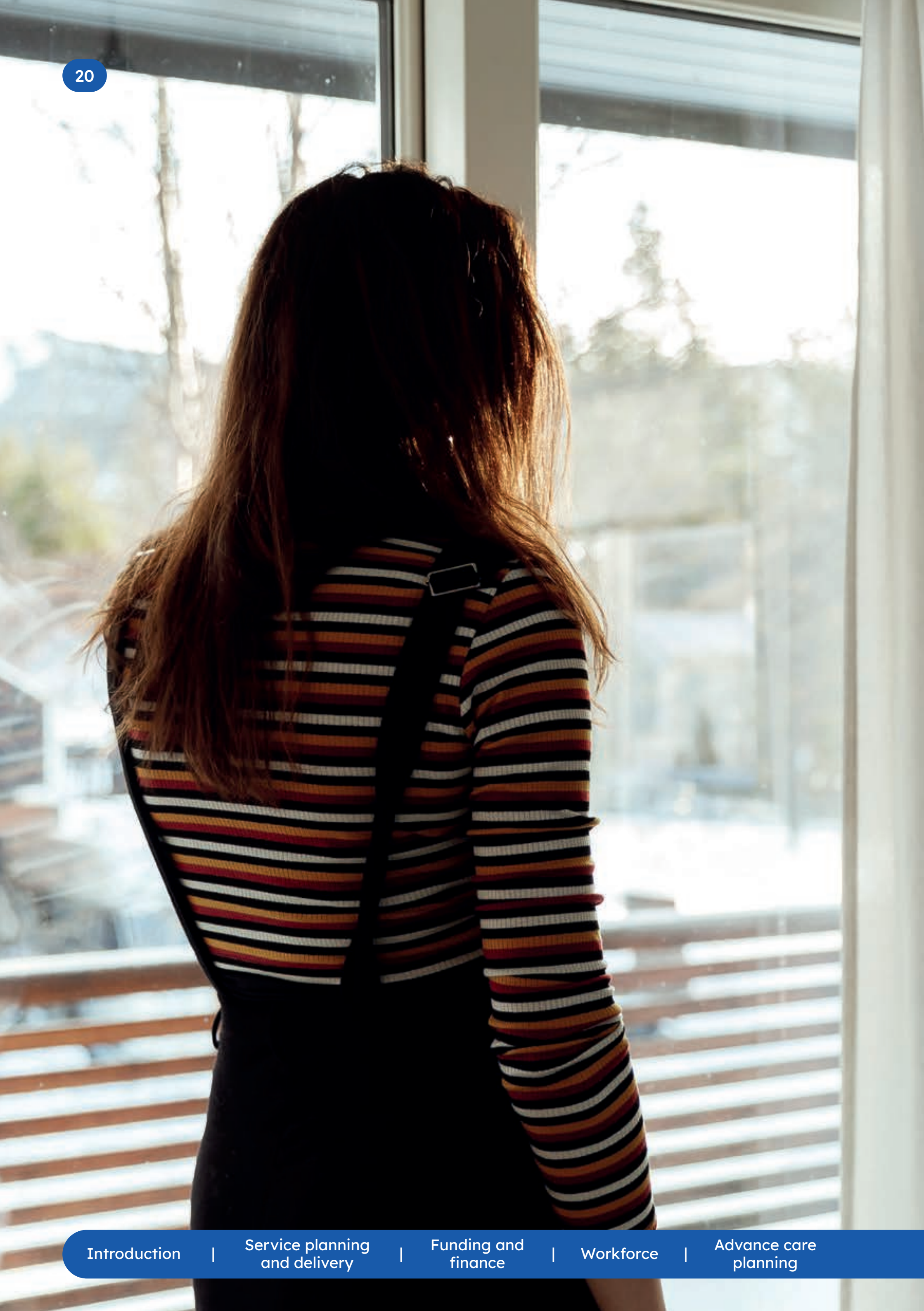
While we lack data to properly understand the scale of the issue in Wales, international evidence shows that many groups are at risk of experiencing inequities in care. Factors such as gender, ethnicity, sexuality, gender identity and being disabled can all create additional barriers to accessing quality palliative and end of life care.[12] Additionally, people experiencing homelessness, prisoners, people with severe mental ill health and those living in more rural areas can face similar challenges.

To tackle this issue in Wales, we must get the basics right. Without a proper understanding of who is and isn't accessing palliative and end of life care, and their experiences of care, we can't design and deliver services that meet everyone's needs.

Enable everyone in Wales to access the same quality of palliative and end of life care, regardless of who they are or where they live.

Actions

1. Undertake a review to determine whether palliative and end of life services across Wales are meeting the needs of minoritised and disadvantaged groups.
2. Improve equality and diversity data collection across all services and feed it into a central point to aid system-wide analysis and improvement.
3. Mainstream equality into the planning, design, delivery and evaluation of palliative and end of life care services.
4. Develop targeted interventions where there is clear evidence of inequity. Pilot new approaches, which can inform system-wide change if proven successful.



8. Unpaid carers

Unpaid carers in Wales play a critical role in providing support and care to people at the end of life, often juggling multiple responsibilities and facing significant emotional and financial pressures. They're often family members or friends and are more likely to be women and be older.[13]

The needs of unpaid carers are neither properly identified nor supported. 54% of bereaved people had helped take the person who died to appointments, 56% had helped with medical procedures and 76% had spent time 'on call', typically for more than 50 hours per week.[14] Many felt they lacked the necessary knowledge, skills and support, with poor communication from professionals and inadequate care coordination causing significant stress.[15]

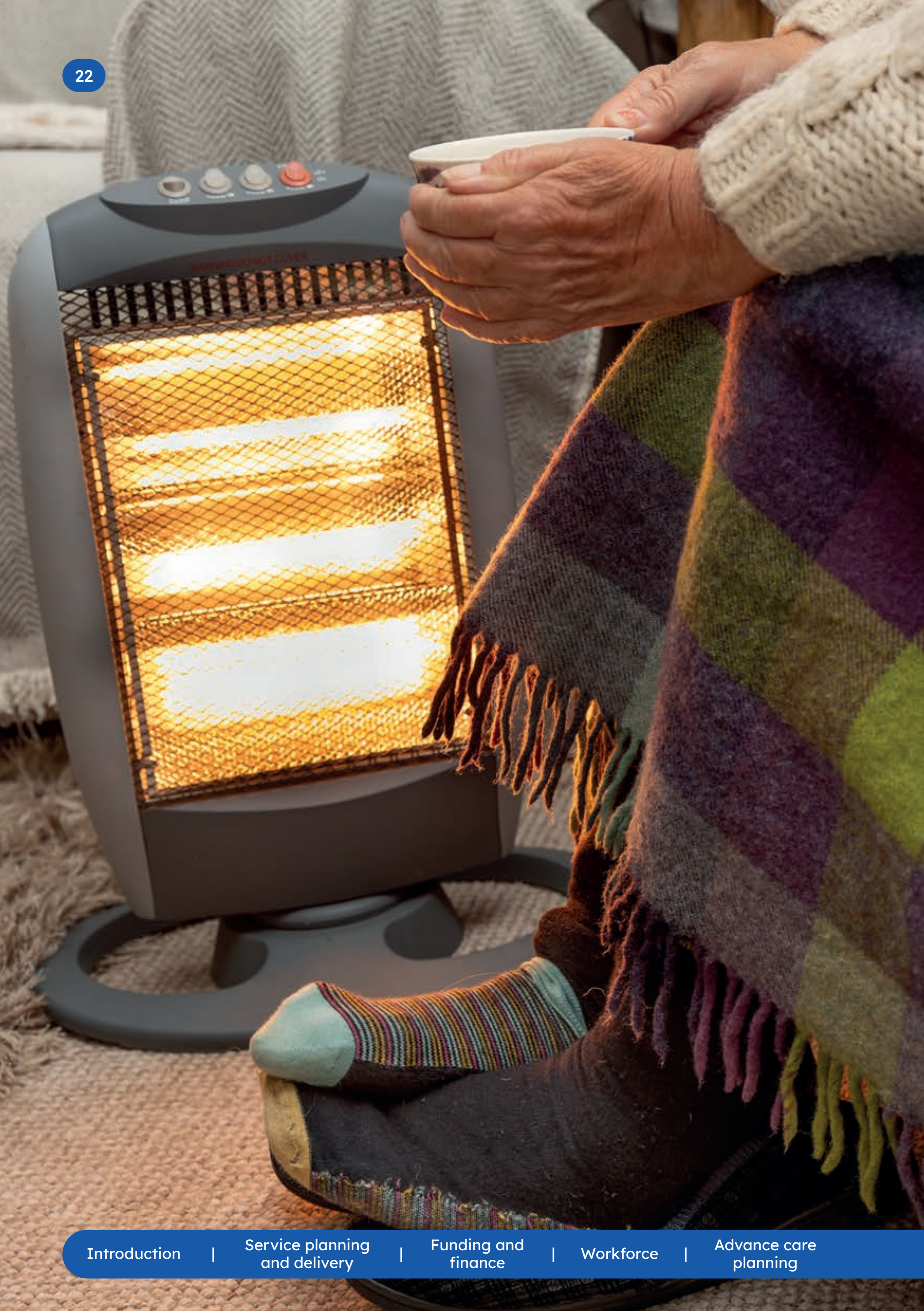
A considerable number of end of life carers in the UK are living in poverty (between 10% and 15%), with the proportion living below the poverty line increasing dramatically in the year following bereavement.[16]

Despite a legal requirement to assess carers' needs and provide support, this isn't happening consistently. Research from Carers Wales suggests just 6% of carers are getting a carer's needs assessment.[17]

Regularly assess and review unpaid carers' needs so they can be provided with the support that they need.

Actions

1. Make information and training resources on the needs of unpaid carers available for the palliative and end of life care workforce.
2. Develop training for unpaid carers in the essential skills needed to care for someone at the end of life. This should be based on existing evidence-based models such as Last Aid and EASE in Scotland.
3. Ensure carers have access to key healthcare contacts including 24/7 palliative and end of life care and support.
4. Consistently undertake and regularly review carers' needs assessments and refer carers to welfare benefits and financial advice and support.



9. Poverty

Too many people are dying in poverty. In 2023, 6,262 people died in poverty in Wales, equal to 17% of all deaths in Wales that year.[18] Wales has the highest proportion of working-age people experiencing poverty in the last year of life (30%), with people in Blaenau Gwent, Cardiff, Newport and Merthyr Tydfil at the highest risk.[19]

In 2022, more than a fifth of people living with a terminal illness died in fuel poverty in Wales.[20] A person's energy bill can rise by 75% after their diagnosis, due to the need to run medical devices, maintain a specific body temperature or simply because of spending more time at home.[21]

Continued inequality means that some people are at a higher risk of living and dying in poverty. Data limitations prevent a comprehensive picture of these issues in Wales, but UK data suggests that women, families with dependent children and minoritised groups are all at a higher risk of poverty at the end of life.[22]

This is not inevitable. Thousands of people can't make the most of the time they have left because of spiralling bills and constant worries about how to make ends meet. Policymakers, service providers and healthcare services must focus their attention on the financial hardship facing people with a terminal illness and those close to them, including family and carers.

Protect people living with a terminal illness from financial insecurity and poverty.

Actions

1. Ensure health and social care professionals routinely and effectively refer people living with a terminal illness and their carers to welfare benefits advice.
2. Include people living with a terminal illness in the Council Tax Reduction Scheme.
3. Introduce additional financial support for people living with a terminal illness to help with energy costs.
4. Task the Welsh Government Equality Data Units with publishing data and indicators on the employment, income and wealth inequalities experienced by people with protected characteristics and the impact this has on poverty at the end of life.

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