Response to the National Carers Consultation

Tenovus Cancer Care is Wales' largest independent cancer charity, with a long and distinguished history of providing practical and emotional support to everyone affected by cancer in their community.

We are committed to working alongside people affected by cancer to champion their needs, raise awareness of the issues faced and ultimately improve cancer outcomes.

The Changing Face of Cancer and its Impact on Carers

The landscape of cancer in Wales is undergoing a significant transformation, shifting from a focus on acute/end-of-life care to the management of a long-term chronic condition. Current data[1] indicates that approximately 190,000 people in Wales are now living with or beyond a cancer diagnosis, a figure that continues to rise as five-year survival rates reach nearly 60%. This shift is driven by both medical advancements and an ageing population; while there are currently around 20,000 new diagnoses annually, this is projected to increase to 24,000 by 2035[2]. Consequently, the "face" of cancer is no longer defined solely by the point of diagnosis or active treatment, but by the thousands of individuals navigating life with the long-term physical and psychological effects of the disease.

However, a stark challenge remains in the form of health inequalities; five-year survival rates in the most affluent areas (69%) remain significantly higher than in the most deprived communities (51%), highlighting that the benefits of this changing landscape are not yet being felt equally across the nation.

The transition of cancer into a chronic, long-term condition significantly alters the responsibilities and wellbeing of unpaid carers across Wales. With more individuals living for decades following a diagnosis, the role of a carer has shifted from providing intensive, short-term support to managing a permanent and often fluctuating set of needs.

Gaps in statutory provision of support for unpaid carers[3] makes community-based support – of the kind offered by the third sector, essential. Services such as Tenovus Cancer Care's nurse-led support lines, professional counselling, and welfare benefit advice are increasingly vital for helping carers of people with cancer and carers with cancer manage both the practical and psychological complexities of long-term cancer care.

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[1] https://phw.nhs.wales/news/overall-one-year-cancer-survival-rate-recovered-since-pandemic-but-long-standing-deprivation-gaps-increase

[2] https://phw.nhs.wales/services-and-teams/observatory/data-and-analysis/cancer-in-wales-trends-and-projections/

[3] https://www.bbc.co.uk/news/articles/cqj8vrg5vxko

Section one

The draft National Strategy for Unpaid Carers sets out eight key priority areas to support unpaid carers in Wales:

1. Recognition and awareness: Increase public and professional recognition of unpaid carers through accessible information, targeted outreach to Black, Asian and minority ethnic people and other marginalised groups, and e-learning for health, social care, and education staff.
2. Access to services: Ensure unpaid carers understand their rights and, where appropriate, receive timely, quality assessments of their needs and support plans.
3. Young carers: Promote recognition and support for young carers within education and community settings, including access to identity cards. Regular assessments to ensure they are not taking on too much. Promotion of improved mental health and educational experience and outcomes.
4. Financial hardship: Provide unpaid carers with information to maximise income and promote benefit uptake.
5. Paid employment: Support for unpaid carers to remain, in or return to, paid employment via promotion of employment rights, carer-friendly workplaces and inclusive employment pathways for carers.
6. Replacement care (respite) and breaks from caring: Improve access to suitable respite options, including short breaks, working with local authorities to identify gaps and co-produce improvements with unpaid carers.
7. Mental health and wellbeing: Enhance carers’ mental health support through local review of support groups, carer-informed generic services, and increased professional awareness.
8. Carers and care planning: Recognise unpaid carers as partners with local authorities and health boards in the assessment, care planning, and hospital discharge for those they care for.

Question 1: Do you agree the eight priorities outlined in the draft strategy at page 1 are the right priorities?

Recognition and awareness

This is a strong starting point, particularly in addressing under-identification. However, recognition must lead to action. There is a risk that carers are identified earlier but still face barriers to accessing meaningful support. Strengthening the link between identification and clearly defined next steps, such as timely assessment and access to support, will be critical to ensuring early recognition translates into improved outcomes.

Access to services

The focus on improving understanding of rights is welcome, but access issues are not solely about awareness. Carers consistently report delays, inconsistency, and fragmented provision across Wales. Greater emphasis is needed on reducing variation and ensuring a more consistent standard of access regardless of location. This is particularly evident for people affected by cancer, where carers often navigate multiple services across health and third sector provision, and delays or fragmentation can have immediate impacts during diagnosis, treatment, and recovery.

Young carers

The emphasis on recognition and safeguarding is positive. However, the strategy could go further in addressing the underlying drivers of young caring roles. Greater focus is needed on prevention, recognising that high levels of caring responsibility among children often reflect gaps in formal support rather than choice.

Young carers consistently report impacts on their education, wellbeing, and future opportunities. While improved recognition within schools is welcome, this should be matched with clearer expectations on education settings to provide flexible, practical support that enables young carers to fully participate and succeed.

There is also an opportunity to strengthen the link between identification and early intervention, ensuring that once young carers are recognised, timely and proportionate support is put in place to reduce the level of care they are required to provide.

This is particularly relevant in the context of serious or long-term illness, including cancer, where caring responsibilities can emerge suddenly and intensify quickly, placing significant pressure on children and young people.

Financial hardship

Providing information on benefits is important, but financial hardship is a structural issue, not just an awareness issue. Many carers experience long-term income loss, increased living costs, and impacts on pensions. This priority could be strengthened to better reflect financial security and sustainability, alongside benefit uptake.

For carers of people affected by cancer, financial pressures can escalate rapidly due to travel costs, time off work, and the intensity of treatment periods, highlighting the need for more proactive and practical financial support.

Paid employment

This is a welcome and often overlooked inclusion. The focus on carer-friendly workplaces is positive, but success will depend on how this is implemented in practice. Stronger expectations or incentives for employers could help ensure this moves beyond awareness into meaningful workplace change.

This is particularly relevant in the context of cancer, where caring responsibilities can be sudden, intensive, and unpredictable, making flexible and supportive employment practices essential.

Replacement care (respite) and breaks from caring

The recognition of respite as essential is clear and important. However, carers consistently report that provision is limited, unsuitable, or difficult to access. The strategy would benefit from clearer commitments to increasing availability and ensuring provision meets a range of needs, including complex care.

For carers supporting someone with cancer, particularly during active treatment or at end of life, access to flexible and appropriate replacement care is critical but often limited.

Mental health and wellbeing

The inclusion of mental health, including suicide risk, is a significant strength. Current actions, however, focus largely on awareness and generic support. There is an opportunity to strengthen this by improving access to specialist, carer-informed support and clearer pathways for those in crisis.

Carers supporting someone with cancer may experience acute emotional distress, particularly during periods of diagnosis, treatment, or bereavement, reinforcing the need for timely and appropriate support.

Carers and care planning

Positioning carers as partners is a strong and necessary shift. However, this remains aspirational without clearer expectations for practice. Consistent involvement of carers in care planning and hospital discharge processes should be strengthened to ensure this is routinely delivered, rather than dependent on local practice.

This is particularly important in cancer care, where treatment decisions, discharge, and ongoing care often rely heavily on carers, who do not always feel meaningfully involved or supported in this role.

Question 3: Do you have any further comments, or are there any other priorities you believe should be included in the strategy?

The draft strategy provides a strong and well-evidenced foundation, clearly shaped by the lived experiences of unpaid carers. The focus on recognition, access, and wellbeing is welcome, as is the positioning of carers as partners in care.

To maximise its impact, the strategy would benefit from a stronger emphasis on implementation, consistency, and accountability. While the priorities are appropriate, their success will depend on how they are delivered in practice across Wales. In particular, there is an opportunity to:

- Strengthen mechanisms to reduce variation in access to support, ensuring a more consistent experience for carers regardless of where they live.
- Clarify ownership and accountability for delivery across Welsh Government, health boards, and local authorities, including how progress will be monitored and addressed where outcomes are not met.
- Ensure that recognition of carers leads to timely and meaningful support, rather than earlier identification without improved access.

There is also an opportunity to strengthen the strategy's focus on prevention and long-term outcomes. This includes reducing reliance on young carers by addressing gaps in formal support, and recognising the structural nature of financial hardship experienced by many carers.

In this context, there may also be value in exploring more direct financial recognition for carers, particularly young carers and those providing substantial levels of care. For example, Scotland has introduced a Young Carer Grant, providing an annual payment to those aged 16 to 19 in recognition of their caring role, as well as a Carer's Allowance Supplement to increase weekly income for adult carers. Similar approaches could be considered in Wales to better reflect the financial realities of caring and provide more tangible support alongside existing provision.

Finally, while the inclusion of mental health is welcome, further consideration could be given to ensuring carers can access timely, specialist, and carer-informed support, particularly at points of heightened pressure or crisis.

This is particularly important in the context of cancer, where caring roles are often shaped by rapid transitions, clinical uncertainty, and long-term impact, reinforcing the need for a strategy that reflects not only the presence of carers, but also the realities of what they are navigating.

Overall, this is a positive and important step forward. Strengthening the mechanisms that underpin delivery will be key to ensuring the strategy leads to meaningful and equitable change for unpaid carers across Wales.

Question 4: There are actions under each priority area. These are listed at pages 7 to 23 of the draft strategy document. Is there anything you'd like to say about any of these actions? You can comment on as many or as few as you wish.

Recognition and awareness

The actions provide a clear approach to improving identification through campaigns and training. To maximise impact, this must be matched by sufficient capacity within services to respond. Systems should ensure that once carers are identified, they are consistently offered timely assessment and access to support, rather than signposting alone.

Access to services

The actions appropriately focus on improving awareness of rights and increasing assessments. There is limited emphasis on reducing waiting times or addressing variation in service availability across Wales. Strengthening expectations around timeliness, consistency, and follow-through of support plans would help ensure that increased awareness translates into improved access in practice.

Young carers

The actions provide a comprehensive framework around identification, assessment, and support, but remain largely reactive. Strengthening preventative approaches would help reduce reliance on young carers where caring responsibilities are inappropriate. Greater clarity on how education settings will be supported and held accountable to deliver consistent, flexible support would further strengthen this area.

Financial hardship

The actions are heavily focused on improving awareness and uptake of existing financial support. While important, this does not fully address the underlying financial pressures experienced by carers. Additional measures to mitigate the longer-term financial impacts of caring, including loss of income and increased living costs, should be considered.

For carers of people affected by cancer, financial pressures are often compounded by the need to take sudden or repeated time away from work, reflecting the mismatch between current employment protections and the realities of cancer care.

Paid employment

The actions appropriately recognise the importance of employment support and employer awareness, but rely largely on promotion and voluntary uptake. There is an opportunity to strengthen this by exploring more formal mechanisms or incentives to support the development of genuinely carer-friendly workplaces.

There are also limitations within existing statutory employment protections. For example, Carer's Leave is currently unpaid and requires advance notice, which can exacerbate financial hardship and does not reflect the often-unpredictable nature of caring responsibilities. In practice, access to leave may also depend on employer goodwill, rather than being a consistently applied right. Strengthening statutory provisions to ensure they are both accessible and financially viable would better support carers to remain in employment.

Further, this is particularly important in the context of cancer, where caring responsibilities often arise suddenly following diagnosis and can intensify rapidly during treatment. Carers may need to respond to frequent appointments, unexpected hospital admissions, and periods of acute deterioration, often with little or no notice. Current employment provisions do not adequately reflect this reality. Greater flexibility within statutory leave, alongside financial support, would help ensure carers are not forced to choose between maintaining employment and supporting someone through cancer treatment.

Replacement care (respite) and breaks from caring

The actions acknowledge the need to review and expand provision, which is positive. Greater clarity is needed on how gaps in availability will be addressed and how equitable access will be ensured across Wales. Clearer expectations or targets for provision would help ensure supply better reflects demand.

Mental health and wellbeing

The actions rightly recognise the importance of mental health and suicide prevention, but focus primarily on awareness and integration into existing services. Strengthening access to timely, specialist, and carer-informed mental health support, particularly at points of heightened pressure or crisis, would enhance this area.

This is particularly important in the context of cancer, where carers are often exposed to sustained emotional strain, uncertainty, and anticipatory grief. Periods of diagnosis, treatment, recurrence, or end of life can place carers under intense psychological pressure, often with limited opportunity for respite. Despite this, support is frequently accessed late or only at crisis point. Ensuring timely access to specialist, carer-informed mental health support is essential to reflect the cumulative and often traumatic nature of caring in this context.

Carers and care planning

The actions clearly set out an expectation that carers should be involved in care planning and discharge processes. Further clarity is needed on how this will be consistently implemented and monitored in practice. Strengthening accountability mechanisms would help ensure this is routinely delivered, rather than dependent on local interpretation.

Question 5: Do you have any further comments, or are there any other actions you believe should be included in the strategy?

The actions set out a clear and comprehensive framework, particularly in relation to awareness, identification, and engagement. To maximise impact, there is an opportunity to strengthen how these actions translate into consistent and measurable outcomes for unpaid carers across Wales.

In particular, consideration could be given to:

- **Introducing indicative timeframes** for key processes, such as carers' assessments and access to support, to help reduce delays and provide greater clarity for carers.
- **Defining clearer expectations for delivery**, including what good looks like in practice across health boards and local authorities, to support more consistent implementation.
- **Strengthening outcome measures**, ensuring that success is assessed through improvements in carers' experiences, wellbeing, and access to support, alongside existing activity-based indicators.
- **Clarifying escalation or improvement processes**, where delivery falls short, to support continuous improvement across Wales.

There may also be value in strengthening preventative approaches within the actions, particularly in relation to young carers, by ensuring that support systems reduce reliance on informal care where this is inappropriate.

Finally, continued alignment with other national strategies will be important to ensure a coordinated and joined-up approach to supporting unpaid carers.

Question 6: Do you have any comment on how we can ensure the strategy continues to reflect the experience and priorities of unpaid carers?

The level of engagement undertaken to inform the draft strategy is a clear strength, and it is evident that the priorities reflect a wide range of lived experiences.

To ensure the strategy continues to reflect the experiences and priorities of unpaid carers over time, there is an opportunity to move from one-off engagement to more continuous and embedded approaches.

This could include:

- **Ongoing, structured engagement mechanisms**, such as a standing unpaid carers advisory group or panel, representing a diverse range of carers, including young carers, working carers, and those from underrepresented communities.
- **Regular feedback loops**, where carers are actively asked to reflect on whether services and support are working in practice, with findings used to inform ongoing delivery and improvement.
- **Use of real-time or near real-time insight**, for example through short, accessible feedback tools linked to services, enabling carers to share their experiences at key points such as assessment, hospital discharge, or accessing support.
- **Greater use of qualitative insight alongside quantitative data**, ensuring that carers' voices and experiences are not lost within high-level reporting metrics.
- **Targeted engagement with groups who are less likely to be identified or heard**, including those who do not self-identify as carers or who face additional barriers to accessing support.

There is also an opportunity to ensure that feedback from unpaid carers is clearly linked to action, with transparent communication about how their input has influenced decisions and improvements.

Embedding these approaches would help ensure the strategy remains responsive, reflective of lived experience, and able to adapt over time as carers' needs evolve.

Question 7: Do you think more could be done to improve partnership working across organisations involved in supporting unpaid carers?

Yes

Question 8: Having read the draft National Strategy for Unpaid Carers, what do you think might be the positive impacts on unpaid carers with protected characteristics as covered by the Equalities Act 2010.

Protected characteristics include age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

The draft strategy has the potential to deliver positive impacts for unpaid carers with protected characteristics, particularly through its focus on improving recognition, access to support, and inclusive engagement.

The emphasis on targeted outreach and accessible information (including different formats and languages) is likely to improve visibility and access for carers who may be less likely to self-identify, including those from minority ethnic communities, older carers, and those facing language or accessibility barriers.

The focus on young carers is particularly important in relation to age, supporting better recognition and improved outcomes within education and wellbeing.

The inclusion of mental health and wellbeing, including suicide risk, is also significant, particularly for carers experiencing compounded pressures. Similarly, the focus on financial hardship and employment may benefit groups disproportionately affected by caring responsibilities, including women.

Finally, recognising carers as partners in care planning has the potential to improve experiences for those who may otherwise feel excluded from decision-making.

The extent of these positive impacts will depend on how consistently and inclusively the actions are implemented across Wales.

Question 9: What challenges or risks to unpaid carers with protected characteristics do you think we should consider more fully when producing the final version of the National Strategy for Unpaid carers?

The draft strategy identifies many of the challenges faced by unpaid carers with protected characteristics. However, there are some risks that may require further consideration to ensure equitable outcomes.

Carers with protected characteristics may experience compounded disadvantage, for example due to disability, language barriers, cultural expectations, digital exclusion, or barriers related to sexual orientation or gender identity. There is a risk that without targeted and proactive approaches, these groups may remain under-identified and less likely to access support, particularly where services are not consistently experienced as inclusive, safe, or culturally competent.

This is particularly relevant where carers are supporting individuals with serious or long-term health conditions, including cancer, where needs can be complex, fluctuate over time, and require coordination across multiple services.

These challenges may be further intensified for carers living in areas of higher social and economic deprivation, where access to services, transport, and support networks may already be limited.

There is also a risk that increased identification is not matched by accessible and appropriate services, particularly for carers supporting disabled individuals or those with complex needs. This could lead to frustration and disengagement if carers are recognised but not meaningfully supported.

For young carers, there remains a risk that support continues to be reactive, with insufficient focus on reducing inappropriate caring responsibilities where these reflect gaps in formal provision.

There is also a broader risk that variation in delivery across Wales may disproportionately impact carers with protected characteristics, particularly where local service provision is already under pressure.

To help mitigate these risks, there may be value in strengthening the use of evidence and ongoing evaluation. Continued engagement with academic partners in Wales, such as CASCADE in Cardiff University, could support a deeper understanding of how different groups of carers experience services and where targeted improvements are needed.

Question 10: Having read the draft Strategy for Unpaid Carers, what do you think might be the positive impacts on young carers and their rights under the United National Convention on the Rights of the Child.

The draft strategy has the potential to deliver positive impacts for young carers, particularly by strengthening recognition, support, and their involvement in decisions that affect them.

Earlier identification of young carers may help ensure their needs are recognised sooner, supporting their rights under the United Nations Convention on the Rights of the Child (UNCRC), particularly the right to be heard and to receive appropriate protection from excessive or inappropriate caring responsibilities.

The focus on education is particularly important. Improved recognition within schools and colleges has the potential to support attendance, participation, and attainment, aligning with young carers’ right to education and development.

The inclusion of mental health and wellbeing support is also significant, particularly where caring responsibilities impact emotional wellbeing. This supports young carers’ right to health and access to appropriate support.

The commitment to involving young carers in shaping services is a further strength, reflecting their right to have their views taken into account in decisions that affect their lives.

Overall, the strategy has the potential to strengthen both recognition and realisation of young carers’ rights, provided that support is delivered in a timely and consistent way across Wales.

Question 11: What challenges or risks to young carers and their rights under the United National Convention on the Rights of the Child do you think we should

consider more fully when producing the final version of the National Strategy for Unpaid carers?

While the draft strategy recognises many of the challenges faced by young carers, there are several risks that may require further consideration to fully uphold their rights under the United Nations Convention on the Rights of the Child (UNCRC).

A key risk is that support remains reactive rather than preventative. Evidence shows that young carers often take on significant responsibilities due to gaps in formal care and support systems. Without a stronger focus on reducing inappropriate caring roles, there is a risk that their rights to rest, play, and development are compromised.

There is also a risk that identification does not translate into meaningful change. Young carers are frequently recognised but continue to experience high levels of responsibility and limited support, particularly where services lack capacity or coordination.

The impact on education and future opportunities remains a significant concern. Young carers are more likely to experience disrupted attendance, reduced attainment, and limited participation in wider school life. These risks can be heightened at key transition points, such as moving between education stages or into further education or employment.

Young carers' mental health and emotional wellbeing is also a key risk area. Evidence indicates higher levels of stress, anxiety, and isolation, particularly where caring responsibilities are intensive or unsupported. This can be especially pronounced where a child is supporting someone with a serious or life-limiting condition, including cancer, where caring roles may emerge suddenly, fluctuate, and carry significant emotional burden.

There is also a risk that some young carers remain hidden or under-identified, particularly where caring is normalised within families or communities, or where stigma and cultural expectations act as barriers to engagement. This may disproportionately affect young carers from minority ethnic backgrounds, LGBTQIA+ young people, or those living in areas of higher deprivation.

Finally, there is a broader risk that variation in delivery across Wales may result in unequal experiences, with access to support dependent on local provision rather than need.

Addressing these risks will be critical to ensuring the strategy not only recognises young carers, but actively protects their rights and supports their development in line with the UNCRC.

Welsh Language Impact Assessment

The strategy’s alignment with Welsh language standards and the *More Than Just Words* framework is a clear strength, particularly in embedding the Active Offer and improving access to bilingual support. Its impact will depend on how consistently this is delivered in practice, particularly across different regions and services.

Question 12: Having read the draft Strategy for Unpaid Carers, what do you think might be the positive impacts on the Welsh language? We are particularly interested in any likely effects on opportunities to use the Welsh language and on not treating the Welsh language less favourably than English.

The strategy is likely to have a positive impact on the Welsh language by strengthening access to bilingual information, services, and support, and reinforcing the principle of the Active Offer. This should increase opportunities for Welsh-speaking carers to use their preferred language, particularly at points of vulnerability, and help ensure Welsh is not treated less favourably than English.

Question 13: What challenges or risks to the Welsh Language do you think we should consider more fully when producing the final version of the National Strategy for Unpaid carers?

While the strategy is broadly positive, a key risk is inconsistent delivery of the Active Offer in practice, particularly across different regions and services. Workforce capacity, including the availability of Welsh-speaking staff, may also impact the extent to which services can be delivered bilingually.

There is a further risk that Welsh language provision becomes reactive rather than proactive, requiring carers to request support in Welsh rather than it being routinely offered.

Addressing these risks will be important to ensure Welsh is consistently available and not treated less favourably than English across all settings.

Question 14: Thinking about this consultation overall, are there any issues that have not been addressed that you think are relevant? If so, please provide details in the space below.

Overall, the consultation is comprehensive and reflects many of the key issues facing unpaid carers. One area that could be strengthened further is the practical delivery of the strategy, particularly how actions will translate into consistent experiences for carers across Wales.

There may also be value in placing greater emphasis on key transition points, including diagnosis, hospital discharge, and changes in caring roles, where carers often experience the greatest pressure. This is particularly relevant for those supporting individuals with serious or long-term conditions, including cancer, where caring responsibilities can emerge suddenly and intensify.

Stronger alignment with related policy areas may also be beneficial. In particular, engagement with those leading on suicide and self-harm prevention could help ensure the needs of carers, including young carers, are more fully recognised within wider mental health and prevention strategies.

Finally, continued focus on prevention and early intervention will be important, particularly in reducing reliance on young carers where this reflects gaps in formal support. This is particularly relevant for cancer, where the point of diagnosis, treatment transitions, and survivorship can create sustained and shifting pressures on carers, underscoring the need for a strategy that is responsive to both acute and long-term caring realities.