A vision for cancer services that match the best in Europe.
They may have long-term side effects such as fatigue, incontinence or lymphoedema. We need a new ambitious approach to match the changing nature of cancer and its treatment, so that many more people survive and many more people live well with and beyond a cancer diagnosis.

In Wales, over 19,000 (WCISU Feb 2015) people are diagnosed with cancer every year and more than 130,000 people are currently living with or beyond cancer, almost 4.5 percent of the population. By 2030 it is expected that 250,000, almost eight percent of the Welsh population, will have had a cancer diagnosis and one in two of us will be affected by cancer at some point in our lives.

The good news is that survival rates are steadily improving and many people recover. On average 70 percent of Welsh residents diagnosed with cancer can expect to survive at least one year. However, improving survival rates in Wales need to be considered in the context of even better survival rates in many other European countries.

Earlier this year, Macmillan Cancer Support released analysis that showed cancer survival rates in Wales are at or behind a level that many other European countries had already achieved by the late 1990s.

Evidence from the The CONCORD-2 global study compared the five-year cancer survival rates for a range of common cancers and revealed that survival rates in Wales for lung, breast, colon and stomach cancer are trailing 10 years behind other European countries. Similarly, a Eurocare 5 population based study reinforces these findings.

We know the NHS is struggling to meet current demand. A transformation in the way we treat and care for patients with and beyond cancer is needed if we are to close the gap between Wales and our European counterparts. Continuing our drive to improve outcomes, quality of life and reduce instances of unacceptable variation for patients in Wales is the challenge we all face.
Welsh Government, the NHS and its partners must respond to the increasing and changing needs of people living with cancer.

To achieve the aims, and meet the challenge, Macmillan wants each political party to prioritise cancer care in its manifesto for the 2016 Welsh Assembly elections and commit to:

1. Cancer remaining a top priority in the next Programme of Government, leading to a new cancer strategy that delivers cancer care, treatment, experience and outcomes which matches the best in Europe, no matter where the person lives, their age or what type of cancer they have.

2. The cornerstone of this ambition should be embedded in the principle of person-centred care, which ensures every cancer patient receives well co-ordinated holistic care and treatment. This care goes beyond the clinical to also address wider social, financial, emotional, practical, psychological and spiritual concerns. This applies to people receiving active treatment, people living with and beyond cancer and people reaching the end of life.

3. Ensuring that avoidable unscheduled admissions for people moving towards the end of life are reduced, supported through the use of Advanced Care Planning tools.

4. Strengthened and transparent national leadership and governance to clearly set out the ambition to deliver on the new integrated cancer strategy.

Macmillan believes that cancer should remain a top priority in the next Programme of Government, leading to a new cancer strategy that delivers cancer care and treatment which matches the best in Europe, no matter where the person lives, their age or what type of cancer they have.

This ambition can only be achieved by working with partners, including the third sector, to provide national leadership to develop a transformational cancer strategy incorporating a detailed implementation plan which sets out the scale of the challenge and how it will be met by 2021.

The patient voice is a pivotal driving force behind delivering positive change. It is Macmillan’s ambition that future cancer strategies are founded upon patient experience and the views of those directly affected by cancer. We would expect the next government to embrace and respond to the insights of surveys such as The Wales Cancer Patient Experience Survey (WCPES) 2014 and successive surveys to ensure that patients’ voices and experiences inform future cancer strategies.

To achieve the level of ambition set out in the new cancer strategy, Macmillan would expect the following to be explicit in all party manifestos:

1. Access to a specialist cancer nurse who is also their key worker from diagnosis and through the acute stages of treatment.

Specialist cancer nurses are part of the cancer multidisciplinary team and are usually recognised as the key worker.

They hold a clinical caseload, co-ordinate wider care and work to promote health and wellbeing in the patients they care for. They use their skills and expertise in cancer care to provide physical and emotional support, coordinate services and to inform and advise patients on clinical as well as practical issues, leading to better patient outcomes. They liaise with other specialists to manage longer-term side effects such as fatigue, pain, incontinence and lymphoedema.

This skilled workforce helps to improve quality of life for people with cancer through holistic needs assessment, assisting the patient with decision making, symptom management and emotional support. Specialist cancer nurses can also help to empower patients to better self-manage their condition. Evidence shows that this professional workforce can lead to reduced costs and efficiency savings for healthcare providers through reduced hospital appointments, emergency admissions and by reducing consultant time.

2. The specialist adult cancer nursing workforce is not expanding sufficiently to keep pace with the growing number of people being diagnosed and living with cancer.

There is an increasing need for continuous investment in cancer specialist nursing roles, particularly in some specific cancer types and locations, further training and professional development in conjunction with redesigning clinical pathways that would make better use of a range of skills and expertise.

Macmillan has worked with clinical teams and stakeholders throughout Wales to understand and evaluate the contribution of specialist cancer nurses to support local planning, workforce and service improvements who are crucial to the delivery of person-centred care in Wales.

3. “No-one had a helicopter view of my care.”

Macmillan’s Welsh Assembly Election Planning Group Member, July 2015

Patients allocated a specialist cancer nurse are more positive about the experience of their care. The results of the Wales Cancer Patient Experience Survey evidence this⁶.
Macmillan believes that to achieve the best outcome following a cancer diagnosis, person-centred care must be at the heart of service delivery. Only by focussing on the whole person, can the patient’s experience during their cancer journey be as good as it can possibly be. This is true for those who survive cancer, are living with cancer or someone who is nearing the end of life.

It means treating people with sensitivity and compassion and ensuring that their care is holistic in its planning and delivery. This goes beyond the clinical to also address wider social, financial, emotional, practical, psychological and spiritual concerns.

There are a number of factors required in order to deliver person-centred care consistently and to a high quality. These are:

- Active involvement of the patient in planning and understanding their care plan
- Personalised and holistic needs assessments and written care planning
- Well co-ordinated continuity of care
- Good communication
- Information and support
- Signposting to financial, practical and emotional support

Assessment and care planning provides an opportunity to engage with people in decisions about their care and generate valuable information to develop a holistic personal care plan. This should include discussions around the experience, skills and expertise an individual can contribute to improving their own outcomes, experience and quality of life.

Macmillan wants to see a consistent approach to assessment and care planning using validated tools used to assess needs throughout the cancer pathway so that people affected by cancer are consistently well-supported. This discussion supports person-centred care and ensures the commitment within the Cancer Delivery Plan are implemented.

Every person with cancer should have a holistic needs assessment undertaken using a validated tool. The outcomes from this discussion, and the actions agreed with the patient should be set out in a written care plan, a copy of which should be offered to the patient.

A care plan should be carried out at the point of diagnosis, and again at the end of treatment or whenever health or wider needs change.

The care plan, developed following the holistic needs assessment sets priorities for care, actions, timeframes and approaches needed to address the person’s needs or concerns.

A written copy of the care plan should be offered to the person affected by cancer as the care plan is ‘owned by’ and supports the individual during and after their treatment. However, the results of the Wales Cancer Patient Experience Survey suggest this is not happening consistently.

Only 1 in 5 cancer patients reported being offered a written care plan. This was a consistent message from patients across all health boards and trusts in Wales.

Macmillan wants to see a consistent approach to assessment and care planning using validated tools used to assess needs throughout the cancer pathway so that people affected by cancer are consistently well-supported. This discussion supports person-centred care and ensures the commitment within the Cancer Delivery Plan are implemented.

“Every person with cancer should have a holistic needs assessment undertaken using a validated tool. The outcomes from this discussion, and the actions agreed with the patient should be set out in a written care plan, a copy of which should be offered to the patient.”

Person-centred care means that the needs of the person living with cancer are always at the heart of how services are planned, not the needs of the service providers.

“Assessment and care planning provides an opportunity to engage with people in decisions about their care and generate valuable information to develop a holistic personal care plan. This should include discussions around the experience, skills and expertise an individual can contribute to improving their own outcomes, experience and quality of life.”

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“Macmillan wants to see a consistent approach to assessment and care planning using validated tools used to assess needs throughout the cancer pathway so that people affected by cancer are consistently well-supported. This discussion supports person-centred care and ensures the commitment within the Cancer Delivery Plan are implemented.”

“My Macmillan Nurse has been wonderful, she made me feel normal. She listened, she passed on information that she thought would help my recovery journey.

“I don’t know how I would’ve coped without Louise because I felt no one understood what I was feeling about what happened and was still happening to me.”

Eirlys, Wrexham
Ensuring that each person diagnosed with cancer receives timely information and support to help them understand their cancer and make informed decisions about their treatment and care.

This will help to deliver improved patient safety, reduce risk and support better self management. To achieve this, improvements in a number of key areas are needed, including:

- Ensuring people regardless of where they live in Wales, or the nature of their condition, have access to high quality information both during and beyond treatment in a format which meets their needs
- Supporting people to easily identify high quality information and drive improvements in quality
- Ensuring the effective use of available resources by clarifying the role of services and integrating information within the care pathways – particularly in relation to support following hospital treatment
- Promoting a shift from healthcare professionals being an information provider to an information enabler, supporting people to access the information and support they need to make decisions and find their own solutions

Ensure that each person who receives a cancer diagnosis is offered the opportunity to access welfare benefits advice.

Each person diagnosed with cancer should be routinely informed where and how to access welfare benefits advice to ensure they are able to access the financial support they are entitled to in a timely manner to help avoid escalating financial difficulties due to their illness.

Having cancer is expensive. Our research shows that more than half of people with a cancer diagnosis in Wales are worried about their finances, and one in four have to cut down on normal household expenditure. One in five people have problems paying their bills, rent or mortgage, and we know from speaking to patients that in extreme cases they’ve become homeless following their cancer diagnosis.

Loss of income is one of the greatest financial challenges for people diagnosed with cancer. 43 percent of those in employment at the time of diagnosis experience loss of income, while the income of spouse, partner or carer might also be affected if they need to give up work or reduce their hours to care for their loved one. Loss of income is greatest in the first year after diagnosis, when the average person loses an estimated 20% - £5,500 in Wales – of their earnings.

Fewer than half of people with a cancer diagnosis in Wales say they receive financial advice or support from any source. This figure falls even further among the over 65s, where fewer than one in three receive support.

Only a quarter of people with cancer discuss their financial situation with a health or social care professional, and this figure is reduced again among the over 65s to just 11%.

“I’m lucky that my husband is working and we have no mortgage, but not everyone’s in that situation. I wasn’t aware I could be eligible for benefits until my nurse told me when I was at hospital. Tina and Rob my Macmillan Welfare Benefits Advisers have been brilliant.”

Judy, Swansea
Ensure that avoidable unscheduled admissions for people moving towards the end of life are reduced and planning for good care should be undertaken in advance of a patient’s condition deteriorating.

Macmillan expects Welsh Government to be committed to the delivery of high quality palliative and end of life care. For people who are no longer curative and are dying from cancer, their ongoing care and treatment needs to be planned holistically. With the support of primary care and through advance care planning, every effort should be made to ensure that people are cared for and, wherever possible, are able to die in the place of their choice. Avoidable unscheduled admissions to hospital during this stage of illness should also be prevented where possible.

Advance Care Planning (ACP) is an important tool to understand people’s wishes, needs and preferences at the end of life and facilitates planning to meet them.

Sadly, if people are not identified as approaching the end of life, and professionals do not initiate conversations to understand peoples’ needs and preferences, it is less likely that plans can be put in place to meet those needs. There is evidence to suggest that the use of processes such as ACP to establish a person’s wishes around their care at end of life can increase the likelihood of those wishes being met.

We believe that, supported by ACP, avoidable unscheduled emergency admissions for people at the end of their life should be prevented through good support in the community across both health and social care. Health boards which have a dedicated End of Life/Advance Care Planning Facilitator in place have demonstrated that it is a highly effective model of care for supporting implementation of care planning and through dedicated education and training for health and social care professionals.

Addressing the National Governance Gap in NHS Wales.

It is not enough for high quality cancer care to remain a top priority for Welsh Government. There also needs to be strengthened arrangements for governance and accountability for ensuring delivery and implementation to be implemented at a national level. We welcome the unified and strengthened arrangements for a single cancer network in Wales and believe that this is a step in the right direction.

However further steps are still required to strengthen national governance and accountability. We believe that without the scale and pace of change needed, Wales will continue to languish and our aspirations to provide cancer care that matches the best in Europe will not be realised.

We believe strengthened national leadership is needed to accelerate the pace of change in terms of delivering agreed policy plans to improve governance arrangements. Our submission to the Assembly’s Health and Social Care Committee’s inquiry into the implementation of the Welsh Government’s Cancer Delivery Plan in April 2014, and our response to its report published in October 2014, reinforced our call for this to happen.

Whilst we recognise the governance arrangements that already exist for health boards and NHS Trust, national scrutiny of individual organisations rests with Welsh Government and cannot be delegated to groups such as the Cancer Implementation Group, nor to health boards, their local populations or third sector organisations. This is the governance gap cannot continue.

The next Welsh Government needs to establish new transparent and strengthened arrangements for managing individual organisations in NHS Wales with the aim of raising performance, building trust with the public, reducing variation and assuring delivery of commitments across.

In Summary...

After the 2016 election, the next Welsh Government must deliver person-centred cancer care that consistently provides every person who receives a cancer diagnosis with outcomes for treatment, care and experience that match the best in Europe.

Macmillan has produced a series of more detailed rich pictures to support our recommendations and provide evidence to support our calls.

GET IN TOUCH

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Macmillan would like to thank the members of the Election 2016 stakeholder engagement group who have supported the development of this vision document for the 2016 National Assembly Elections.

For a copy of these, or for more information about our recommendations for the next Welsh Government, please contact:

Lowri Griffiths
Policy and Public Affairs Manager
lgriffiths@macmillan.org.uk

or

Matthew Kennedy
Policy Officer
mkennedy@macmillan.org.uk
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