

## The 2022 Northern Ireland Assembly Election Macmillan Cancer Support Manifesto Calls

- 1) The Executive's next budget should deliver a multi-year cancer workforce funding settlement and commence the next phase of Cancer Nurse Specialist expansion, ensuring Northern Ireland recruits 100 more Cancer Nurses Specialists by 2030.
- 2) The next Executive should deliver personalised integrated care for everyone with cancer. Through implementation of the Cancer Strategy's recommendations everyone should be offered a holistic needs assessment and signposted onto emotional, practical and financial support in their community.
- 3) The next Health Minister should publish an annual progress report on closing health inequalities in cancer care.
- 4) The next Executive should fund a strategic transformation of Palliative and End of Life care through delivering cancer strategy actions to ensure everyone who needs it can access integrated and personalised care when and where they need it.
- 5) Everyone living with cancer should be offered emotional and wellbeing support which is tailored to their individual needs.

The coronavirus pandemic delivered a devastating blow to cancer care in Northern Ireland and people living with cancer have experienced lengthening waiting times, surgery cancellations and a persistent cancer care backlog. We want the next Assembly to ensure that cancer does not become the forgotten 'c' of the pandemic, services have been in a fragile state for many years and this must be resolved to ensure people are never again exposed to the disruption of recent years. This election is a critical fork in the road, a Cancer Strategy has been published but the next Executive will need to have an unwavering focus on delivering the transformation of cancer services that people in NI need and have been promised. Funding is urgently needed to deliver this Strategy and the Executive's first budget will be a pivotal moment.

*This election is the chance to push Cancer to the top of political parties agendas. Cancer does not discriminate, it affects people in all our communities. This disease has caused untold suffering to many people in this country. Maybe the parties will agree to sustained funding for treatment, research and support for people in our communities who are living with this disease daily. - A member of our Cancer Experience Panel*

## Workforce

**Our manifesto recommendation: Provide through the next budget a multi-year cancer workforce funding settlement and deliver the next phase of Cancer Nurse Specialist expansion, ensuring Northern Ireland recruits 100 more Cancer Nurses Specialists by 2030.**

Health and Social care staff have gone above and beyond to meet the challenge of Covid-19 and to minimise disruption to cancer care. They must be supported to meet the next challenges of rebuilding services, tackling the backlog in cancer care and working with a potentially more complex cancer care population.

In rebuilding cancer services we need to learn from the past and tackle the systemic workforce challenges that left services stretched before the pandemic and consistently missing the Executive's waiting times targets. This can be done by moving to a long-term demand based modelling approach to commissioning services and providing a multi-year funding settlement for the cancer workforce plan, including the next phase of the Cancer Nurses Specialist workforce expansion.

Clinical Nurse Specialists are experienced cancer nurses who advise, treat and manage the health concerns of people with cancer. They play a critical role in delivering person centred care throughout the pathway. Patient experience illustrates this, the latest NI Cancer Patient Experience Survey highlighted access to named Clinical Nurse Specialist led to increased positive experiences across most questions<sup>i</sup>. Recent research demonstrated that if the number of specialist cancer nurses stays at current level, by 2030 NI would be 100 Clinical Nurse Specialists short to provide the care that people need<sup>ii</sup>. It take many years before investment in training reaches the frontline of care, achieving the necessary number of Clinical Nurse Specialist for 2030 will require sustained investment through the next budget.

***"Great, caring and compassionate – I could not speak highly enough" - A Cancer Experience Panel member on the cancer workforce***

### **Personalisation:**

**Our manifesto recommendation: The next Executive should deliver personalised integrated care for everyone with cancer. Through implementation of the Cancer Strategy recommendations everyone should be offered a holistic needs assessment and signposted onto emotional, practical and financial support in their community.**

Northern Ireland's cancer care system is facing unprecedented challenges. Many people living with cancer report that they do not receive personalised care now and research<sup>iv</sup> predicts a significant increase in the next decade of people who will have been diagnosed with cancer at some point in their lives.

Health and Social Care should deliver fully personalised care that meets people's full range of physical, emotional and practical support needs. Personalised follow-up care when provided in NI has been shown to increase people's ability to self-manage and has also been linked to cost efficiencies<sup>v</sup>. Failing to identify and support people's needs early in their cancer care will result in poorer outcomes and experience for people living with cancer, this could result in

greater pressure on the health and care system later where unmet needs become more severe or reduce individuals' ability to self-manage their health.

The Cancer Strategy identifies many of the components required to deliver integrated personalised care and outlines an ambitious vision. To ensure the strategy fulfils this vision the next Executive will need to prioritise access to Holistic Needs Assessments (including electronic assessments), expanding access to navigation support and providing an equitable regional range of services available to meet emotional, practical and financial needs.

*"The care I got in hospital was lovely. The minute I got home I felt lost and scared. You feel like you are vulnerable, and you have a big label on you that screams cancer, sometimes you don't want to bother the nurse. I feel completely forgotten about"* A quote from a person living with cancer

*"In hospital you are looked after with such care, but when you are discharged, you are on your own and you have to fight to get anything at all"* A quote from a person living with cancer

### **Inequalities:**

**Our Manifesto recommendation: The next Health Minister should publish an annual progress report on closing health inequalities in cancer care.**

Health inequalities exist at all points of the cancer pathway, not just in contributing to the development of cancer, but also impacting on what type of treatment you might receive, your ability to access support and your overall survival.

Collection of data on inequalities within the system is only useful if there is also a plan on how we use that data to close the inequality gap. To make meaningful progress on reducing health inequalities, the next Health Minister should commit to set out in an annual progress report their approach for how health inequalities are being tackled across the cancer system.

As part of this work, inequalities metrics must be identified in the cancer strategies data framework and should then be reported on alongside the Minister's annual health inequalities report. It is also vital that lesser heard groups are involved with this work, to better understand their experience of the current system and what improvements need to be made.

*"Data is essential for understanding how cancer services in Northern Ireland are performing and for driving service improvements in care quality and outcomes for patients. Data is critical in achieving the world-class service promised within the draft NI Cancer Strategy 2021-31."* A quote from a member of the Cancer Experience Panel

### **End of Life Care:**

**Our manifesto recommendation: The next Executive should fund a strategic transformation of Palliative and End of Life care through delivering cancer strategy actions to ensure everyone who needs it can access integrated and personalised care when and where they need it.**

The most recent All Ireland Institute of Hospice and Palliative Care<sup>iii</sup> survey showed that 67% of respondents said if they were living with a serious illness, they would prefer to have palliative care at home. If we are to facilitate more people dying at home and taking into consideration that Northern Ireland has a growing and ageing population, it is clear that there needs to be continued investment in the community and in specialist services.

The cancer strategy sets out the steps needed to be taken in order to improve palliative and end of life care, but it is vital that these plans are supported by the investment needed to deliver the changes required.

***1 in 4 people would feel their doctor is giving up on them if they talked to them about palliative care - AllHP survey***

## **Mental Health:**

**Our manifesto recommendation: everyone living with cancer should be offered emotional and wellbeing support which is tailored to their individual needs.**

It is critical to identify and support mental health early on in cancer treatment. Macmillan's analysis of 1,600 people with cancer across the UK, revealed that nearly half (46%) of people living with cancer report having emotional support needs, with a third (33%) reporting they would like more support.

We also saw in the most recent NI Cancer Patient Experience Survey a reduction between 2015 and 2018 in people finding someone on the hospital staff to talk to about their worries and fears during their hospital visit(s) (from 70% of respondents down to 53%). This evidence clearly indicates that there is unmet need for emotional support for people living with cancer.

The findings underline the importance of a well-defined, integrated psychosocial care pathway to ensure that individuals are accessing timely support that is relevant, appropriate, and sufficient for their needs.

This support should take a holistic approach across the whole journey, including after treatment and should recognise the impact of physical health on emotional wellbeing. There is also a need to focus on providing support for people living with cancer's wider network. This is important as we know family and friends are the most significant source of support for people living with cancer with emotional needs, but that they don't always know how to provide effective mental health support and may be struggling to cope with the fallout from the cancer diagnosis themselves.

***"Having cancer can be a very lonely and isolating place to be" " You need someone to come and talk to you, to sit down with you and say...here's how we can help you" Quotes from people living with cancer***