Losing our Patience

Tenovus Cancer Care's priorities for fairer, faster cancer services



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Our priorities for the year ahead

Fairer, Faster Cancer Services – our collective efforts will centre on delivering on our five policy calls:



Gynaecological cancers

Tenovus Cancer Care continues to call on the Welsh Government and NHS to fully implement the findings at speed of the Senedd's Health and Social Care Committee's report Unheard: Women's journey through gynaecological cancer.

Many of the women who shared their experience with the Committee believed that healthcare professionals did not listen to their concerns nor take their symptoms seriously.

Women talked about their experiences being tantamount to 'medical gaslighting' where they were led to question their confidence around what was happening to their own bodies and some felt they were made to feel they were being neurotic the more they reported unusual symptoms.

While steps have been taken to tackle some of the points raised in the report, more needs to be done to address the issues around women's health concerns not being taken seriously.

It's disappointing that the report did not reference the life-threatening challenges women with gynecological cancer face within our health systems.

Tenovus Cancer Care is calling on the next Welsh Government and senior leaders to:

 Reconsider the exclusion of gynaecological cancer in the Women's Health Plan and include gynaecological cancer as part of a review based on the Plan being published as a live and iterative document.



Lung cancer

Lung cancer is the biggest cancer killer in Wales - more than breast and bowel cancer combined. One year (41 %) and five-year (18.2%) survival rates lag slightly behind those of Scotland and England.

Of the most common cancer types, lung has the widest cancer death inequality, with higher incidence and mortality in areas of economic deprivation. The size of the differences in mortality between more and less deprived areas has also increased over time.

The clinical and financial benefits of screening are overwhelming - with a targeted lung cancer screening programme in Wales having the potential to save hundreds of lives across the country.



There is nothing, now or on the horizon, that would make a bigger difference to cancer mortality and cancer inequality in Wales than introducing a national lung cancer screening programme.

Dr Sinan Eccles

Respiratory Clinical Lead, Targeted Lung Cancer Screening Scoping Project



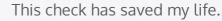
Tenovus Cancer Care is calling on the next Welsh Government and NHS leaders to:

Deliver a targeted lung screening programme urgently.

Meet Phil

Phil, a smoker for over 50 years, was invited to take part in a pilot lung cancer screening progamme run by Cwm Taf Morgannwg University Health Board. He was subsequently diagnosed and treated for the disease.

I had no symptoms so I wouldn't have put myself forward or sought any help as life was fine as far as I was concerned. I was invited to attend my screening, and I had no hesitation in taking up the invite.





Less survivable cancers

Cancers of the lung, pancreas, liver, brain, oesophagus and stomach have an average five-year survival rate of less than 20 per cent. For people who have one of these six cancers, early and fast diagnosis is critical to detecting the cancer at an early stage when a cure is possible.

Wales can no longer afford - morally nor financially - to neglect the less survivable cancers and their impact on our communities. A concerted effort, focused on all six, must be an integral part of any collective effort to build and deliver sustainable cancer services. The cost of failing to act now is simply too great.

It need not be a zero-sum game either. The actions needed to drive improvements and deliver better outcomes for less survivable cancers will have positive net effects on the rest of the NHS. Treatments would be less costly, delivered over a shorter period, often in the community and likely leading to less rehabilitation time. As a result, NHS capacity and resources would be unlocked.

Tenovus Cancer Care is calling on the next Welsh Government and senior leaders to:

 Recognise the six less survivable cancers, their unique characteristics, their impact on Wales and plan accordingly.

PANCREATIC LIVER BRAIN OESOPHAGEAL STOMACH

The numbers

An estimated **120,000** people are living with cancer in Wales today

Around **20,000** people are diagnosed in Wales every year

By the end of the next Senedd term, an estimated **230,000** people in Wales will be living with cancer

50% of diagnoses are at stage 3 or 4



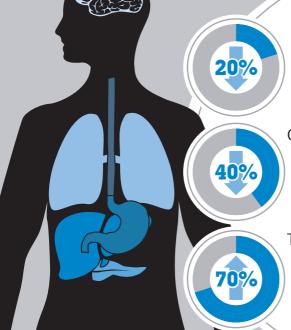
The less survivable cancers have an average five-year survival rate of LESS THAN 20%

One-year survival for a patient diagnosed with a less survivable cancer in Wales is

LESS THAN 40%

This contrasts sharply with the overall one-year survival rate for all cancers, which is

OVER 70%



Money, practical support and cancer

A cancer diagnosis leads to unforeseen costs which can quickly mount up. The sudden and unexpected loss of income, coupled with hidden costs, such as heating, extra washing and travelling to and from appointments, can place an enormous burden on people.

The cost of living crisis has compounded these challenges as food and energy costs have risen sharply, forcing many to make tough choices over heating or eating.

Everyone with cancer deserves a welfare benefits check-up with an Advice Quality Standard (AQS) accredited advisor to ensure income from financial entitlements are maximised and they can discuss practical support. As well as supporting the person in greatest need, the money finds its way into local communities across Wales, supporting the foundation economy.

To reach this point, Wales must move away from the current opt-in system for welfare benefits advice - where a referral is at the request of the person affected by cancer. This relies on people knowing roughly what they need and having a healthcare professional who knows of - and has the time to refer onto - a welfare benefits pathway. We want Wales to start moving towards an opt-out system where the referral is a systematic part of a holistic cancer pathway.

Tenovus Cancer Care is calling on the next Welsh Government and senior leaders to:

 Assume all cancer patients need benefits advice and commit to exploring shifting referrals from the current opt-in model to one that is opt-out, using the cancer pathway as a model for other health conditions.

Meet Bethan

Bethan received support from Tenovus Cancer Care Benefits Advisors after being diagnosed with breast cancer when she was just 26 years old.

Beth was reluctant to stop work, but there came a point where she had to sign off sick. She was entitled to statutory sick pay and Personal Independence Payment (PIP).

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Tenovus Cancer Care has helped massively during the most difficult times.





Emotional wellbeing

Alongside the physical trauma of a cancer diagnosis and the subsequent treatment regime, people affected by cancer may experience a wide range of feelings and emotions that might lead to them needing support.

In a past Wales Cancer Patient Experience Survey, only 20 per cent of people diagnosed with cancer received information about psychological support and 58 per cent of people felt their mental health wasn't taken as seriously as their physical health.

No mental health support, no benefits or financial referral or support. In my experience there was no holistic care looking at me as an individual and what I and my family might need given I had a terminal metastatic breast diagnosis.

It was not until my treatment finished and I was left to get on with life I went into a kind of shock. I broke down approximately two months after, I felt lost, alone, and did not know what to expect. This did shock me as I am a very strong person. I've spoken to others with cancer and have found this is quite common, it is only then you realise you have cancer.

Tenovus Cancer Care is calling on the next Welsh Government and senior leaders to:

Ensure the Strategic Network for Cancer work with their NHS Health Board partners to implement the All Wales Cancer psychology Project, reducing variation of availability, awareness and access to psychological support.

Meet John

John, from a rural farming community in Denbighshire, used Tenovus Cancer Care's Counselling service while coming to terms with his terminal cancer diagnosis.



My counsellor understood entirely what I was going through. I could talk to someone independently of everyone else who knew me, and she was good.

She advised me to make myself a priority, which was hard to do, but I knew I needed to put my own health first. To concentrate on me.





Conclusion

At the heart of everything we do are people affected by cancer right here in Wales.

Woven throughout our priorities is the need for Welsh Government to listen to and learn from these voices. When patient voices are sought and heard, a clearer picture emerges of what is happening on the ground, and better solutions can be found.

Since 2022, we have worked hard to develop our All-Wales Cancer Community - a patient involvement network spread across Wales whose voices have fed into hundreds of projects run by health care providers, researchers, policy makers and other third and private sector partners.

Find out more:

tenovuscancercare.org.uk/awcc









Share your story

We'd like to hear from you as your story can help us reach more people through personal testimony. By becoming a media volunteer and sharing your cancer story with us, you can help us raise awareness, drive change, and help others feel less alone.

Interested? Get in touch on the email below and our team will get back to you to arrange the best way to share your story.

stories@tenovuscancercare.org.uk

Thank you