

CANCER CARE IN WALES

WE ARE
MACMILLAN.
CANCER SUPPORT

People with cancer must be at the heart of cancer care and their experience of care is just as important as the medical treatment they receive.

That's why in 2016, Macmillan Wales and the Welsh Government ran the second Wales Cancer

Patient Experience Survey to capture the views of people who have had cancer care.

More than 6,700 people who had cancer in Wales took part and the results will be used to improve cancer care and support across Wales in the future.

What do people in Wales who've had cancer treatment think about their care?

 **93%**

The vast majority of people surveyed rated their care as highly positive, with **93%** of patients selecting a rating between seven and ten (on a scale of 0-10 where 10 = very good).

 **89%**


89% of people said that they were treated with dignity and respect

But there is room for improvement, particularly around discussing and developing a care plan (only 18% were given one), offering people written information about their cancer and information on how to access financial help. There is also variation in people's experiences according to where they live and what type of cancer they had.

The key worker

 **86%**

The Wales cancer plan says every person with cancer in Wales should have a key worker as a single point of contact and to coordinate their care. **86%** of people said they had the name and contact details of their key worker.

 **26%**

But more than a quarter (**26%**) said it wasn't always easy to contact their key worker.

Deciding on the best treatment and care for you



97% of people surveyed said they had their treatment options explained before their cancer treatment started.

But only **56%** said they were definitely told about future side effects.

Emotional, practical & financial support

 **61%**

61% said their family was definitely given all the information they needed on how to care for them at home.

 **48%**

Only **48%** of people said they had been given information about financial help and benefits.

 **45%**

Less than half of people (**45%**) said the impact of their cancer on their day to day activities was completely discussed with them.

Diagnosis



84% said they were told they had cancer sensitively.

But **21%** said their GP didn't take their symptoms completely seriously before their diagnosis.



These differences were especially noticeable in people's experience of non-clinical care. For example, **73%** of people with a CNS said they'd been given the right amount of information about support and self-help groups compared to just **36%** of people who did not have a CNS.



(And **95%** of people with a CNS said they had been given the name and contact details of a key worker compared to less than half (**46%**) of people without one although well over half of people surveyed said their CNS and key worker was the same person.)

The Clinical Nurse Specialist



Most patients (**81%**) were given the name of a Clinical Nurse Specialist to support them through their treatment.

But more than a third (**37%**) said it wasn't always easy to contact their CNS.



One of the key factors in having a good experience is having access to a Clinical Nurse Specialist

For almost every question, people who had a Clinical Nurse Specialist (CNS) reported having a better experience. This includes:



82% of people with a CNS said they had definitely been as involved in decisions about their care and treatment as they wanted to be compared to **67%** of people without one.



67% of those who had a CNS said they had been told about voluntary and charity support. This fell to **29%** among those without one.



95% of people with a CNS said they were told who to contact if they were worried after leaving hospital. This falls to **79%** for people without a CNS.



85% of people with a CNS said they had been given understandable written information about side effects whereas only two thirds (**66%**) of people without a CNS said they had received this.



People with a CNS were more likely to have received information about how to access financial help or benefits. **55%** of people with a CNS said they had had this compared to less than a quarter (**23%**) of those without one.



55% of people who had a CNS said they had been given the opportunity to discuss their needs and concerns to develop a care plan compared to **25%** of those who did not have a CNS.



The results of this survey, along with the results of the first survey, demonstrate the overwhelmingly positive impact having a CNS can have on people's experience of cancer care. That's why Macmillan

Wales wants every person with cancer in Wales to have access to a Clinical Nurse Specialist to coordinate their care and support them throughout their treatment. We also believe the Clinical Nurse Specialist should act as the key worker for people with cancer.