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# **CHANGING CANCER CARE IN WALES**

A report by  
Macmillan  
Cancer  
Support

March 2011

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# Foreword

We have carried out an extensive three-year research programme across Wales to understand what people living with and after cancer need – and how well the cancer care system meets those needs. As part of this process we spoke to people who have experienced cancer themselves, as well as to academics and professionals working in Welsh health and social care.

Our research clearly shows that the current system of tackling cancer is costly and simply doesn't meet people's needs. Given the growing number of people diagnosed or living with and after cancer, the burden this is placing on the NHS and other service providers, and the current economic climate, we believe it is financially and morally vital for the next Welsh Assembly Government to prioritise cancer care in Wales.

We recognise that right now budgets are limited. But the evidence in this report shows that if we put the right support services in place now – and improve coordination and communication across agencies and throughout the cancer journey – we can meet the needs of people with cancer and use resources more effectively.

It is also clear that people living with and beyond cancer, as well as professionals and managers, want to see a change in the way cancer care is delivered in Wales. We believe we all have to work together to transform cancer care so that we can meet people's changing and increasing needs. And that we must develop a national, person-centred cancer strategy to make this transformation happen.

As a small country, Wales is in a unique position to redesign its cancer services. The National Assembly for Wales election in May gives us the chance to take a more radical approach to the way we treat and care for people living with and after cancer in Wales. And to provide services that are more cost-effective and meet the needs of the whole person.

We are confident that Wales can develop cancer services that are among the best in Europe and we want to help the next Welsh Assembly Government make this a reality. It is our hope that the government will take up the recommendations and solutions offered in this report. We believe that together we can improve the lives of people affected by cancer in Wales.

**Cath Lindley**

General Manager for Wales,  
Macmillan Cancer Support

# Summary and recommendations

**Cancer is a complex disease. With over 200 different types, treating it is becoming more complicated and expensive than ever before.**

Diagnosing cancer at an early stage is a major challenge for Wales. We know from studies carried out elsewhere in the UK that if people were diagnosed earlier and offered appropriate treatment more quickly thousands of lives could be saved.<sup>1</sup> But it is no longer simply a matter of whether people survive cancer or not. Thanks to advances in early diagnosis and treatment, more people are living longer with cancer or beyond it, which means they need ongoing and often long-term support. By 2030, it's estimated that the number of people living with or after cancer in Wales will nearly double to almost a quarter of a million.<sup>2</sup>

Cancer and its treatment can have a devastating impact on people's lives. At the same time, the current cancer care system is expensive and doesn't meet people's needs. To provide people in Wales with the cost-effective care and support they need during and beyond cancer, we must radically transform care.

What we need is a comprehensive, person-centred cancer strategy for Wales. One with clarity, vision and direction. A strategy that has a wide-ranging, whole-systems approach to preventing, diagnosing, treating and caring for people with cancer, that takes into account the growing number of people living with cancer, advances in technology and the challenging economic times.

We believe the new strategy should include four key initiatives to make cancer care in Wales more person-centred: improved assessment and care planning, reforms to follow-up care, more personalised information and support and a key worker for everyone with cancer. Such a strategy will enable cancer services to move away from a one-size-fits-all approach to more individual care throughout the entire cancer pathway. This will ensure better outcomes for people living with and after cancer, while research has shown it will save money too.



However, a strategy alone is not enough. Deciding where to allocate funding is a difficult decision for the Welsh Assembly Government, the NHS and local authorities. Strong leadership is needed to support managers and clinicians to take the right decisions. Strong national leadership is also essential to maintain a focus on implementation and ensure consistency and equality across the country so that no matter where they live, everybody receives the same high quality treatment and care.

At Macmillan, we have been working to improve the lives of people living with and after cancer for 100 years. Every year we invest millions of pounds in improving cancer services in Wales. Our research and experience show us what people in Wales want and need. Now our commitment is to work with the next Welsh Assembly Government to help deliver world-class cancer care for our nation.



## What we recommend

1: Develop a person-centred cancer strategy for Wales in the first year of the next Assembly term.

Wales needs a national cancer strategy that recognises the changing nature of the disease and leads the way to transforming cancer care. It must incorporate the entire cancer pathway – from prevention and survivorship to palliative care and end of life – and meet the needs of people living with cancer.

The key theme running throughout the new cancer strategy for Wales should be that all treatment and care is person-centred. A definition of person-centred care can be found on page 17.

It is critical that the development of the strategy involves the people in Wales who understand the issues best: stakeholders who support people living with and after cancer, and those who have experienced cancer firsthand.

2: Include four key initiatives within the cancer strategy to achieve person-centred, cost-effective cancer care.

By adopting these changes over the next

Assembly term, we can improve care and achieve a more coordinated and efficient use of NHS resources.<sup>3</sup>

- i. Improved assessment and care planning
  - o Every cancer patient should be offered an assessment and care plan at each appropriate stage of their cancer journey.
- ii. Reforms to cancer follow-up care
  - o After their initial treatment, every cancer patient in Wales should receive ongoing support that is tailored to meet their own level of need and risk.
- iii. More personalised information and support
  - o Everyone living with cancer should be offered tailored information and support throughout their cancer journey.
- iv. Access to an identified key worker
  - o All cancer patients should have access to an identified key worker who understands their needs and is able to support them during and after treatment.

# Part 1: The need for change

## Where we are now

**Wales faces many enormous challenges in supporting people to live with and beyond cancer, as well as caring for those who sadly die of the disease.**

These challenges have been recognised by the Welsh Assembly Government<sup>4</sup>, whose ambition is to see Wales take its place among the best in Europe by 2015. But as other European countries continue to improve and the deadline approaches, much needs to be done before this ambition can become a reality.<sup>5</sup>

This important work must be accomplished within the changing context of cancer. Today, the diagnosis and treatment of the disease is becoming evermore effective as advances in technology and medicine are made. As a result, many more people are living through cancer, with ten year survival rates doubling over the past 30 years to 46%.<sup>6</sup> For many, cancer is still a short-term incurable illness, but for thousands of others, their experience of cancer is evolving to a long-term condition with many possible outcomes. As the nature of cancer changes, so do the needs of people who are affected by it – and the range of health and social care professionals and services required to help meet those needs.

This transformation is also taking place during very challenging economic times for the NHS and the public sector. Difficult decisions about the allocation of limited resources must be made over the next few years. Leadership and clarity from the government on its vision and ambition for improving cancer services are essential to support decision makers at every level of cancer care, and service and policy development.

It is clear that we must transform the way we deliver cancer care in Wales if we are to meet the needs of the growing number of people affected by cancer in the current climate. Cancer services in Wales need to be more person-centred – a view that people living with and working with cancer support.<sup>7</sup> And we know that if services are more integrated and better coordinated, we can not only achieve better outcomes for people affected by cancer, but also release considerable savings

for the NHS and other statutory partners.<sup>8</sup> However, delivering high quality services that are person-centred and cost-effective requires a step change that will not happen overnight and cannot happen without leadership and intervention from the government and service planners.

As we approach the Assembly's fourth term, Wales has a unique opportunity to be at the forefront of efforts to transform cancer care to meet the needs of people affected by cancer and meet the tough financial challenges that lie ahead.

## How many people are affected?

**When it comes to cancer, Wales faces some significant challenges. The number of people diagnosed with cancer has increased over the last ten years. While survival rates are improving, they still lag significantly behind those in Europe and other developed countries<sup>9</sup>. And as survival improves and our population ages, there are growing numbers of people living with and beyond cancer<sup>10</sup>.**

### KEY FACTS

- 50 people are diagnosed with cancer every day in Wales – more than 17,000 every year.<sup>11</sup>
- Right now, more than 120,000 people are living with or after cancer in Wales – around 4% of the population.<sup>12</sup>
- If current trends continue, by 2030 this will have almost doubled to more than 7% of the population.<sup>13</sup>
- Wales has the highest proportion of people living with cancer in the UK, this is related to having the oldest population of the four nations.<sup>14</sup>
- A higher proportion of people die from cancer in Wales as compared to the rest of the UK. The age standardised cancer mortality rate in Wales is 183 deaths per 100,000 population compared to 176 deaths per 100,000 population in the UK.<sup>15</sup>



## Advances in diagnosis and treatment

As breakthroughs in technology and drug therapies are made, diagnosis and treatment for cancer patients improves and greater numbers of people live through and beyond cancer. If we are to achieve even better survival rates, it is critical that we continue to invest in research and technological advances that will deliver improved clinical care and patient outcomes.

We also need to develop an approach, structure and process that enables healthcare professionals to implement the latest advances in treatment and diagnostics – once they are proven and cost effective. For Wales to achieve a world-class service this can't be left to chance. Clinical leadership at all levels are needed to ensure this vital task is properly managed, so that patients receive the best and latest care, wherever they live in Wales.

## The financial challenge

Cancer accounts for 7.1% of all NHS expenditure in Wales<sup>16</sup>. In 2008-09 this amounted to £358.8 million – the fourth highest area of expenditure for the NHS after mental health, circulation problems and trauma and injury.

As the number of people diagnosed and living with cancer increases, the cost of cancer services is set to become an increasing financial burden on the NHS.

While the cost of cancer drugs and treatments is undeniably high, evidence shows that we can make other efficiency savings in cancer care. For example, by providing assessment and care planning, information provision, benefits advice and personalised one-to-one support through clinical nurse specialists – we can use resources much more efficiently. As well as reduce unnecessary bed days and emergency admissions for cancer.<sup>17</sup>

Research carried out by Monitor on behalf of Macmillan<sup>18</sup> has also shown that more coordinated cancer care can lead to savings. The report highlights opportunities to save money by:

- improving communication, coordination and information

- improving care in order to reduce length of stay after treatment, outpatient follow up, hospital deaths, and GP consultations
- supporting patients to return to work

The report concludes that improving care coordination, reducing avoidable emergency admissions and the length of stay in hospital, and enabling more people to die at home, could generate NHS savings of up to 10% for the cancer patients it examined through the study. It also found that the UK economy could be boosted by £30 million every year if just five per cent more breast cancer survivors were better supported to stay in work.<sup>19</sup> This would represent a substantial boost to the economy in Wales.

Additional research<sup>20</sup> shows that when you take health service costs and lost productivity into account, the total cost of cancer to the UK in 2008 was £18.33bn. This is set to rise to £24.72 billion by 2020. But if cancer services and survival rates improve enough to be among the best in Europe, that figure could be reduced by £10bn in England alone, saving a staggering 71,500 lives. Improvements like these could also be achieved in Wales.

The evidence is clear: cancer impacts the wider community, society and the economy. The next Welsh government must set a clear vision for cancer services so that planners can focus on investment priorities and identify areas where savings can be made through innovation and improved care. A national strategic approach to cancer will encourage greater savings by minimising duplication in front line services, encouraging innovation and helping to make best practise common practise.

## Cancer is different now

Twenty years ago, cancer was considered to be a death sentence for many people and the aim of treatment was often just to extend life for a few months. Now, improvements in diagnosis and treatment mean that 60% of people with cancer will live for five or more years<sup>21</sup>. For some cancers, such as breast, five-year survival rates are as high as 80%. Because of this, cancer is no longer simply kill or cure. For an increasing number of people, it is a chronic illness that may follow a relapse and remission pattern over several years.

Interestingly, perceptions of cancer and the way care is provided haven't kept pace with these developments<sup>22</sup>. Recent research for Macmillan – with professionals working in cancer care in Wales – found that while they acknowledge that the cancer landscape is changing, they also recognise that services are not evolving with it<sup>23</sup>.

This changing nature of cancer poses a significant challenge for the NHS, social services and the voluntary sector as they seek new and better ways to meet the needs of people with cancer and use their limited resources effectively.

## What do people want and need?

**People affected by cancer tell us that the disease turns their lives upside down. It affects how they feel about themselves and those they care about, their work, finances and emotional wellbeing. On a practical level it has a huge effect on their ability to live their day-to-day lives. And they feel these impacts throughout their cancer journey.**

According to professionals working in cancer care in Wales, the dominant focus of care is still a clinical one – 'of treating the condition rather than the individual'.<sup>24</sup> As a result, many of the other needs that people with cancer have are left unmet. Professionals have expressed their frustration that non-clinical needs are often poorly addressed. They speak of the need to challenge a clinical culture 'that often believes that as long as you get the medical and physical side of care right, that is adequate care'.<sup>25</sup>

### Emotional and psychological needs

*'It would be nice if, when being told you have cancer, you are also informed of emotional services to access...you need to learn how to fight this thing because you are likely to be thinking I'm going to die.'*<sup>26</sup> *Person affected by cancer, Wales*

Cancer places people under extreme emotional and psychological strain, which can lead to a huge range of practical difficulties in daily life.<sup>27</sup> At the time of diagnosis, around 50% of people with cancer experience levels of anxiety and depression severe enough to affect

their quality of life. For 25% this continues for the following six months. In the year after diagnosis, around 1 in 10 people living with or beyond cancer will experience symptoms so severe they need specialist psychological or psychiatric services.<sup>28</sup>

Research shows that lung, pancreatic, Hodgkin's lymphoma, brain, head and neck, leukaemia and lymphoma patients experience the highest levels of distress.<sup>29</sup> We also know that more patients find the emotional effects of cancer most difficult to deal with compared to the physical or practical effects, and that this is particularly the case for women, those with young children, and those from lower socio-economic backgrounds.<sup>30</sup>

For these reasons people with cancer often need emotional support when they are diagnosed, as well as during and after treatment. In spite of this, people say they find it difficult to persuade professionals to refer them to more help. Although some people need professional psychological support to help them deal with the effects of cancer, many simply need someone to talk to.

*'I was very lonely and poorly in health when I left hospital. I had lots of complications like infected scars, which lasted six to seven weeks. Nurses treated the sores but had so much paperwork to see to they had no time to talk.'*<sup>31</sup>

*Person affected by cancer, Wales*

Our own recent research has shown that 20% of the people with cancer said they wanted counselling while they had cancer but less than half were told where they could get it.<sup>32</sup>

*'I was given a booklet which explained various cancers and treatments but at the time of diagnosis in the clinic that was all. I was upset and would have liked someone to talk to.'*<sup>33</sup>

*Person affected by cancer, Wales*

Professionals surveyed by Macmillan agree that the emotional impact of cancer is not being addressed and that people living with and after cancer are often left to deal with the devastating after effects alone.

*'Patients and relatives have to source their own support at a time when they are floundering. Those who need rehabilitation and psychological support to live with their disease or former disease do not get it.'*<sup>34</sup> *Allied Health Professional, Wales*





### **Financial needs**

Studies show that cancer can have a significant impact on people's finances and lead to new or increasing debts.<sup>35</sup> Evidence also suggests that financial burdens can increase anxiety and stress, with some people feeling that financial difficulties are 'more of a worry than the cancer'.<sup>36</sup>

Over 5% of people living with or beyond cancer – over 10% if they are self-employed – lose their home after being diagnosed.<sup>37</sup> 91% of households with people affected by cancer experience loss of income and/or increased costs. For instance, a person with cancer makes, on average, 53 trips to hospital during the course of their treatment.<sup>38</sup> Heating and other household bills can also go up, special diets may need to be catered for and new clothes may have to be bought.<sup>39 40</sup>

Many people living with and after cancer never claim the benefits they are eligible for. This is particularly the case among elderly and disabled people, who often need help to make a claim.

A recent Macmillan survey found that in terms of patients receiving advice following treatment, just 6% of Welsh adults had someone talk to them about money issues such as benefits and grants, and just 3% had

someone talk to them about work worries or issues.<sup>41</sup>

Our research suggests that worrying about money is second only to pain as a cause of stress to people with cancer.<sup>42</sup> We need to make sure that people with a cancer diagnosis receive the financial benefits they are entitled to so they can be free to focus on their treatment and recovery.

### **Information needs**

People living with cancer, and their carers, need sound information and support to help them negotiate their way through cancer treatment and beyond. With the right information they have the power to make the best choices for themselves and their family.

Most people with cancer say they would like more information. Some say they don't receive any information at all.<sup>43</sup> A recent survey done on our behalf found that 72% of cancer patients in Wales wanted information about their condition, 77% wanted to understand the long-term effects of treatment, and 71% wanted to know about the different treatment options available. Unfortunately, less than 33% of people with cancer who took part in the survey actually received this information.<sup>44</sup>

As cancer and its care changes, we need to



support people living with or after cancer to take an active and leading role in their recovery. The right information empowers people to make decisions about their own treatment, but it needs to be given in a way that is meaningful. We welcome the recent efforts of Public Health Wales to improve health literacy and increase people's understanding of their condition and treatment. Now more work needs to be done to make sure everyone living with and after cancer is offered personalised information and support to manage their condition.

People living with and beyond cancer tell us that easy-to-understand information, support and signposting to other services aren't in

place everywhere in Wales. Where information and support are available, many people don't realise they exist.

*'The staff in the hospital were very caring and excellent. (But) I had no information from the social services on how to get help with care at home on my own and no idea about how to get help.'*<sup>45</sup>

*Person affected by cancer, Wales*

A recent survey of professionals<sup>46</sup> reveals that although information is increasingly available, people often find it overwhelming, especially when first diagnosed. The professionals also say that people need more time to absorb what they are told and to have the opportunity to ask questions outside the consulting room.

One nurse surveyed said:

*'Whilst information is available it is not always given in ways that inform. Medics usually try to explain treatment options etc in terms of percentages, figures from trials, quoting five-year survival rates, which can cause distress as patients only hear "five years". They focus on this, feeling that they have been given a prognosis. Often they are sent away with no checking of understanding and are expected to make a decision with this information and no psychological support to do so. I guess what I am trying to say is that information is there, often in copious amounts, but it is not person-centred.'*<sup>47</sup>

*Cancer Nurse, Wales*

### **People's long term needs following treatment**

While people are receiving treatment for cancer, they are supported by a variety of professionals in the hospital, going from appointment to appointment. But once treatment has finished, much of the support disappears even though people can continue to have a range of complex physical, psychological and social needs. People can experience chronic illness – such as bowel problems, chronic fatigue, lymphoedema, impotence, infertility and depression – while new cancers or treatment-related conditions can emerge months or even years later.

In spite of the many problems that follow cancer treatment, people living with or beyond cancer tell us there is a lack of support.<sup>48</sup> They talk about the period after treatment as one of abandonment. Many compare it to feeling like they are on the edge of a cliff.

A survey conducted on our behalf found that 60% of people living with or beyond cancer want information, advice and support about next steps and choices in the cancer journey after treatment. Only 23% get it. It also found that 27% of people who complete their treatment feel abandoned by the health system.<sup>49</sup>

*'After treatment is the part of the cancer journey that's surprisingly one of the hardest. The after effects of treatment mean there's so much toxins and poison going through your body you're affected both physically and mentally. I found it very, very hard.'*<sup>50</sup> *Person affected by cancer, Wales*

*'It does feel like after your last chemo session you are on your own. It's then when you are not so much supported by the nurses, doctors etc that it hits home what has happened and the 'mental health' element kicks in. That is where I feel support is lacking.'* *Person affected by cancer, Wales*

Research carried out for us by the Welsh Institute of Health and Social Care<sup>51</sup> shows that services offered after treatment were the least likely to be person-centred. It found that people are often 'left adrift' once treatment finishes, just when the need for support is most pressing. Professionals in the study recognise the need to provide post-treatment assessment and care planning but say this rarely happens. They are aware of the many practical and emotional difficulties faced by people in the post-treatment stage and feel that people with cancer and their carers would benefit from better signposting towards sources of information and non-clinical support.

Several described the 'long shadow of fear' that cancer casts over people's lives and the need to regain confidence in their own health.

*'There is still an overwhelming response of abandonment following treatment which has not improved. The promotion of living with cancer initiatives is extremely slow in availability.'*<sup>52</sup>

*Operational Manager, NHS Wales*

### **A recent survey carried out in Wales on our behalf by YouGov reveals that<sup>53</sup>:**

- 50% of people living with or beyond cancer say no one talked through their needs after their clinical treatment finished.
- 61% say they didn't receive any support from key health and social care professionals after treatment
- 56% say they were not given a named health professional to help support them in their first year after treatment.
- Of those who did have someone to talk to about their post treatment needs, 76% said these were not written into a care plan.



## The quest for coordinated care and high quality services

**The complexity and severity of cancer makes it challenging but vital to deliver the right services, as quickly and efficiently as possible.**

Diagnosis can be delayed for a number of reasons including late presentation by the individual, poorly coordinated referral systems between services and complex diagnostic pathways.<sup>54</sup> People's cancer treatment plans also vary significantly, depending on the type of cancer they have and the process of diagnosing it. Their plan can include complicated and potentially harmful treatments such as surgery, radiotherapy, chemotherapy and hormone therapy. The effects of new, advanced treatments are unknown but we know that cancer and its treatment can impact someone's life for weeks, months and years to come. At the same time, the care they receive takes place in many locations and often goes beyond local health board and cancer network boundaries. Some specialised treatments happen across UK borders and in other European countries.

This complexity makes it difficult to achieve joined-up care within the healthcare system and the primary, community, social care and voluntary sectors. Continuity of care can suffer and people report feeling as though they are falling into the gaps between service providers. This is what healthcare professionals in Wales say about it in recent research:

*'Individual professionals are kind, but the systems and processes are disjointed so it can be very confusing and reliant on a sole person to provide coordinated care and take overall responsibility'<sup>55</sup>*  
*Person affected by cancer, Wales*

If people aren't given a clearly defined pathway of care – from surgery, chemotherapy or radiotherapy to supported self-care – that helps them access the support they need at any given moment, there is a danger they will turn up at accident and emergency. Then they will be seen by professionals with no knowledge of their condition or history, which leads to expensive, poor quality support.

People living with and after cancer tell us that services are patchy and inconsistent across Wales.<sup>56</sup> This view is echoed in other recent reports, which we will touch on here.

### **Failing to meet standards**

In 2005, the National Cancer Standards were launched to provide guidance for cancer management in Wales. Healthcare providers were asked to meet these standards by March 2009.

In May 2010, the Welsh Assembly Government released a compliance analysis<sup>57</sup>, which shows there are substantial gaps in the availability of cancer services across Wales, with significant non-compliance in almost all areas. All but one local health board achieved less than 50% compliance. The services with least compliance were for the assessment of ongoing support, and prompt access to specialist psychological support.

Not only does the report highlight how much performance varies across Wales, it also suggests that services vary depending on the type of cancer a person has.

### **Late diagnosis and referral**

A recent Cancer Research UK (CRUK) report, says that one of the main reasons that cancer outcomes in the UK lag behind some European countries is that it is often diagnosed late.<sup>58</sup> According to the report, up to 10,000 deaths could be avoided each year in the UK if cancer was diagnosed earlier. There is also hard evidence that cancer is being detected and diagnosed later in Wales and that this plays an important part in the country's poor survival rates.<sup>59</sup>

Research we commissioned from the Wales Institute for Health and Social Care (WIHSC)<sup>60</sup> reveals that professionals working in cancer care in Wales say that some improvement has been made in diagnosing people earlier. At the same time, however, the report notes that people and their GPs are often too slow to act on symptoms and that poorly coordinated referral systems can delay diagnosis even more.<sup>61</sup> And that while most people appear to progress relatively swiftly once a diagnosis is made, it's a different story if the diagnosis and treatment are more complicated. This may

be related to the nature of their disease – for instance, it may be a rare cancer. But it was reported that people who had to be referred to other areas often experienced unnecessary delays because of poor communication between services.

In England, the National Awareness and Early Diagnosis Initiative (NAEDI) has helped raise awareness of the importance of early diagnosis. According to Cancer Research UK, the NAEDI has had a positive impact on the cancer workforce and helped them understand and prioritise early diagnosis. Wales must have a similar national approach to improve early diagnosis if it is to achieve its aim of ranking among the best in Europe on early diagnosis and survival.

### **Access to treatment**

In 2008, we surveyed the then 22 local health boards in Wales to get a clearer picture of the funding process for people who want treatment that isn't routinely offered on the NHS.<sup>62</sup> The surveys revealed a 'postcode lottery', both in terms of how easy it is for people to navigate this 'exceptional funding' process, and the factors that ultimately affect funding decisions.

In late 2008, the government commissioned a report to improve the availability of medicines in Wales.<sup>63</sup> The report, published in January 2009, recommended national guidelines were produced within six months to support LHBs to apply a more consistent and nationally agreed approach to exceptional funding requests. At the time of going to print, as far as Macmillan is aware, national guidelines have still not been shared with LHBs.

### **End of life services**

We know that 67% of people in Wales would choose to die at home.<sup>64</sup> But only 26.1% actually do.<sup>65</sup> When the end-of-life wishes of people with cancer are not met because of a lack of services, it can lead to very traumatic experiences for them, and a lasting sense of guilt and remorse for friends and family left behind.

Often, terminally ill people with cancer are admitted to hospital unnecessarily, which is distressing for them and costly for the NHS. In England, the National Audit Office

### **What our research revealed about access to treatments not approved by NICE:**

- All Welsh local health boards (LHBs) have a process for the exceptional funding of treatments, but with 15 different names.
- While most LHBs make information on their exceptional funding process available to the public, only around one-third said the process is actively promoted.
- Only 6% of respondents in Wales said that there was an oncologist on the decision making panel for cancer treatments.
- 67% said they take personal circumstances into account, such as age, dependents and marital status.
- Two LHBs said that local publicity and media activity plays an active part in their decision making.
- One LHB considers the stage of the financial year at which the application is received.

estimates that by reducing emergency hospital admissions for people with cancer by 10%, and the average length of stay by three days, £104 million a year could be released to help people choose the place of care they prefer.<sup>66</sup> This evidence is supported by Hospital Care at Home – a recent joint report by Healthcare at Home and Dr Foster – which estimates that NHS savings of £160 million could be made if end of life care was delivered in the home.<sup>67 68</sup>

We welcome the recent work of Professor the Baroness Iloria Finlay and the Implementation Board to improve palliative cancer care in Wales. Huge strides have been made in this important area, but more work is needed to improve out-of-hours services, support for carers and care for people in nursing homes.





# Part 2: A national, person-centred cancer strategy for Wales

## Where we are now – existing policies

Cancer care has improved in Wales over the last decade thanks to the introduction of the All-Wales Cancer Standards and the Designed to Tackle Cancer policy statement. But we are concerned that without clear vision and a comprehensive national strategy for cancer, Wales will not achieve the world-class, cost-effective and person-centred cancer care it needs.

### **Moving on from the All-Wales Cancer Standards**

People recognise that the existing cancer standards, drafted in 2005, are no longer wide-ranging, ambitious or person-centred enough to achieve the changes needed to cancer care in Wales. As they stand, the focus is on measuring systems, processes and limited clinical targets. Not on monitoring the quality of those services, the experience of people receiving care, or any improvement in the outcome for people living with or beyond cancer.

The standards were developed as a result of the Calman Hine report, which examined cancer care services in the UK more than a decade ago.<sup>69</sup> At the time, the priority was to improve minimum standards in Wales, and establish a set of core requirements for professionals working in cancer care.

Since then, the nature of cancer and how we treat it has changed. So have the constitutional and political landscape, the philosophy and structure of the NHS, and the expectations of people living with and after cancer.

### **Is the Designed to Tackle Cancer policy enough?**

While other countries develop their thinking around person-centred cancer services, Welsh policy lags behind with an approach that is still dominated by the clinical and acute aspects

of care. Overall, statements and commitments are followed by little action: as with the cancer standards, implementation has been patchy.

We commissioned research<sup>70</sup> to compare the approach to cancer policy in Wales with other countries in the UK, Europe and beyond. We found that it is ‘not at all certain’ that Wales will achieve its 2015 targets, set out in Designed to Tackle Cancer (DTTC).<sup>71</sup> Especially as other countries continue to improve.

Our research highlights that DTTC focuses on only four general areas: prevention, early detection, improved access and better services. This leaves out the important new areas of ‘living beyond cancer’ and ‘patient-centred care’, which feature in the strategies of other countries.

The report describes a ‘somewhat piecemeal approach’ to cancer planning in Wales, which can be attributed in part to ‘changing ministers, two periods of organisational change, changing priorities, methods of commissioning and planning’. After looking at the progress of cancer treatment and care elsewhere, the report concludes that a dedicated cancer strategy is the ‘fundamental building block’ to Wales becoming one of the best cancer care providers in Europe.

In a report by Cancer Research UK<sup>72</sup>, the charity says, ‘Cancer plans are important and useful. They set direction and make the best use of resources’. One of their chief recommendations is that, ‘A more comprehensive plan should be developed to ensure consistent delivery, implementation and integration across Wales’. The report also recommends that Wales should develop a ‘survivorship initiative’; an issue that ‘is an important and emerging policy area, which should be fully embedded in the patient care pathway’.

Research shows that health professionals are also frustrated by the lack of a comprehensive cancer strategy for Wales.<sup>73</sup>

## Other policy and strategy developments

Right now, Wales doesn't have a single, comprehensive strategy that plans for the entire cancer pathway. In 2010 a number of additional policies emerged:

- In March, the Cancer Services Coordinating Group published the Living With and After Cancer report, which recognises the importance of clinical professionals seeing survivorship as a distinct phase of cancer care.
- In May, the Welsh Assembly Government published The National Standards for Rehabilitation of Cancer Patients<sup>74</sup>, which also addresses issues relating to survivorship.
- The Minister for Health, Edwina Hart, announced a new policy that aims to provide every person in Wales living with and after cancer with a key worker by March 2011.

Wales now has around 20 different strategies, frameworks and policies that relate to cancer care, which you can see in the table below. This policy overload has become so complex and fragmented it's virtually impossible to have a clear vision of how best to meet the needs of people living with and after cancer.

### **A list of some of the current strategies, policies and frameworks relating to cancer care in Wales:**

- Delivering Beyond Boundaries: Transforming Public Services in Wales
- Delivering a Five-Year Service, Workforce and Financial Strategic Framework for NHS Wales
- Annual Operating Framework
- Designed to Tackle Cancer in Wales (2006) and subsequent work plan (2008-2011)
- The National Cancer Standards
- The Rural Health Plan
- Setting the Direction: Primary and Community Care Strategic Framework
- Sustainable Social Services for Wales: A Framework for Action
- Workforce strategies e.g Community Nursing Strategy, Designed to Work
- Financial Inclusion Strategy
- Older People's Framework

- Carers Strategies (Wales) Measure 2010
- 2008 'Sugar' recommendations and the work of the Palliative Care Implementation Board
- Cancer screening programmes, such as bowel, cervical, breast
- Symptom awareness programmes
- Chronic Conditions Management Strategy
- Lymphoedema Strategy
- The CSCG Living With/After Cancer report
- The work of the Self Care Board
- Wellbeing Through Work
- NICE Supportive and Palliative Care Guidance
- The Gold Standards Framework
- Integrated Care Pathway

## Developing an effective cancer strategy for Wales

**We know that dedicated cancer strategies increase commitment from the government and raise the profile of cancer in the workforce. This in turn helps to reduce inequalities in cancer care.<sup>75</sup>**

We recognise that many of the Welsh Assembly Government's general health policies and strategies are working towards person-centred, cost-effective care. Now we need a specific strategy to achieve these changes for cancer too.

Such a strategy will:

1. Provide clarity and vision for everyone involved in planning and delivering cancer care in Wales.
2. Provide a framework to embed clinical leadership at national, network and local level.
3. Change the way cancer is considered and planned.
4. Set out a clear expectation that health, social care and voluntary sector providers must work together to provide a seamless treatment and care pathway.
5. Improve the delivery of coordinated, person-centred cancer care at every stage, from prevention, diagnosis and treatment to after care or end of life.





6. Help to develop more innovative, high quality, cost-effective ways to deliver care.
7. Encourage partners to adopt best practice.

### **What would an effective cancer strategy look like?**

We commissioned research to review cancer strategies across a number of countries.<sup>76</sup> We used the results of this research to create a template that you can see in the box on page 16. Our aim is for the next Welsh Assembly Government to be able to use this template to develop a cancer strategy that builds in best practice from around the world.

We know from our research that a strategy cannot be written or exist in isolation. To be effective, it must take into account every aspect of the cancer control system, from funding to evaluation.

### **The importance of leadership and collaboration**

It takes strong leadership to develop and implement every element of a comprehensive strategy that involves a wide and dispersed range of stakeholders. Such leadership is critical if we are to transform the cancer care system and the delivery of services – and achieve the necessary cultural shift in the understanding of cancer amongst health and social care professionals this requires.

People living with and after cancer are experts by experience and should also be involved in the development of the new strategy. Strong leadership is needed here too, to inspire, provide direction and foster collaboration amongst stakeholders.

Effective and determined political, managerial and clinical leadership are essential if Wales is to achieve cancer care that meets the needs of people living with cancer and uses NHS, social care and other resources efficiently.

## Our person-centred cancer strategy template, based on international best practice.

### Vision and objectives

- Express a vision that aims to reduce cancer, increase survival rates and helps people live healthy, productive lives after diagnosis.
- Address inequality: even in countries where there have been significant improvements in care, these are not always offered fairly.

### Country profiles

- Include a country profile with an in-depth analysis of the statistics and issues relating to patterns of disease. Comparisons are also useful.
- Explore resource allocations and service delivery patterns for cancer, to help identify gaps and prioritise future developments.

### The individual's journey

Create the strategy from a personal journey perspective, including:

- Prevention and promotion
- Early diagnosis and screening
- Service delivery
- Palliative care
- Improving the quality of the individual's experience.

Personalised care has become more emphasised. This is an emerging field, which requires further development and engagement with people living with and beyond cancer, carers, families and society in general.

- Living beyond cancer.

This new development recognises that many people will now live beyond cancer – or with it as a chronic illness rather than an acute and terminal episode – and focuses on developing services beyond healthcare. Consider including personalised lifetime follow-up plans, psychosocial support and access to financial support.

### Infrastructure

Consider the national infrastructure needed to support the implementation of the strategy.

### Research

- Allow extra funding for research, which plays a pivotal role in strategy development.
- Emphasise the need to transfer research findings into clinical practice quickly and to improve access to clinical trials.

### Information and IT

There are two core elements to consider:

- The provision of accessible information to the public, patients and professionals.
- The development of data collection and analysis through minimum datasets.

### Workforce development

It is important to have sufficient and well-trained staff. Allow for recruitment, retention, training and continuing professional development.

### Capital and technology

Consider and plan for what access to technology will be needed, such as PET scanners and medicines, as well as the development of centres of excellence for cancer treatment.

### Funding

Identify and plan the funding available for cancer services. This may vary according to how far there is responsibility for this nationally, overall allocation and the new monies being targeted at specific developments.



# Part 3: How do we deliver person-centred cost-effective cancer services?

## Firstly: what does 'person-centred care' mean?

The key theme running throughout the new cancer strategy for Wales should be that all care is person-centred. A good first step is to define exactly what we mean by this.

### **A definition of person-centred care**

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.

It means treating people with sensitivity and compassion and ensuring that their care is holistic in its planning and delivery.

This care goes beyond the clinical to address wider social, financial, emotional, practical, psychological and spiritual concerns.

Putting people at the centre of care planning means they<sup>77</sup>:

- are given the opportunity to express their views, which are listened to and respected
- receive the care they need, when it is needed, regardless of organisational boundaries – and if a service can't be provided they are told why
- know where and how to access ongoing support and information.

A new person-centred approach for cancer services in Wales means moving away from focusing on processes, systems and clinical targets to developing services that meet people's needs – both clinical and non-clinical – throughout their cancer journey.

### **The call for cultural change**

Support for a change in the way cancer care is provided is overwhelming. It is also clear that the transformation from traditional, clinically

led care to a more person-centred model will involve a dramatic change in attitude and culture.<sup>78</sup> The health and social care workforce will need to understand the implications of cancer as a long-term condition as well as an acute one.

There must also be some important shifts in the approach to care and support for people living with and after cancer, to bring greater focus on recovery, health and wellbeing.

Firstly, a shift will need to take place in the way coordination and communication are handled within the health service and the social care and voluntary sectors.

Secondly, greater emphasis is needed on making sure people are well informed and empowered to manage their own condition. To make this a reality, the relationship between healthcare professional and the person living with or beyond cancer has to be transformed from simply care-giving and receiving to creating a partnership that focuses on achieving agreed health and care outcomes. Many professionals will need help to make this transition. They need training that will enable them to assess people's needs, provide meaningful information, solve problems and identify services within and outside the health system.

### **Measuring the quality of services, people's experience of their care and the outcome**

Many of the government's emerging health strategies, and the changing NHS in Wales, recognise that the way we deliver health and social care needs to change. In some cases specialised services need to be delivered in centres of excellence, while in many other cases, support needs to be offered closer to people's homes. These strategies recognise that wherever care is delivered, it should be tailored to the individual's long-term needs, more integrated and better coordinated.

We believe these new generic health and social care developments offer a unique opportunity to update cancer policy in Wales. By reflecting

the care aims of the new five-year strategic framework for the NHS<sup>79</sup>, Wales will be in a strong position to make cancer care more effective, person-centred and cost efficient.

To achieve this, when new targets or standards are set for cancer care in Wales, we need to put more emphasis on monitoring quality of service, the person’s experience of their care and the outcome.

Recent work by Macmillan involving people living with and after cancer, their carers, those working in cancer care and other stakeholders has established how care and treatment should be experienced from the perspective of the person living with cancer.<sup>80</sup> This work has led us to arrive at nine key outcomes we believe all cancer care should aspire to:

We strongly urge the government to consider these nine outcomes in any new targets and standards that are developed as part of a national, person-centred cancer strategy for Wales.

<b>I was diagnosed early</b>	<b>I understand, so I make good decisions</b>	<b>I get the treatment and care which are best for my cancer, and my life</b>
<b>Those around me are well supported</b>	<b>I am treated with dignity and respect</b>	<b>I know what I can do to help myself and who else can help me</b>
<b>I can enjoy life</b>	<b>I feel part of a community and I’m inspired to give something back</b>	<b>I want to die well</b>

## Towards personalised and holistic care

When care is well coordinated, and referrals and signposting are effective, people living with and beyond cancer get what they need, when they need it and in the way they want it. It avoids duplication, wasted or ineffective visits and – more importantly – it ensures that people don’t get lost in transition between organisations and professions.<sup>81</sup> Our research – backed by statements from the government’s own strategies<sup>82</sup> – confirms that person-centred and cost-effective services go hand in hand.

We recognise that changes in the perception of cancer as an illness that is both acute and long-term, and the move towards person-centred care, won’t happen overnight. Changes to cancer care need to be carefully planned, implemented and monitored. They cannot happen without the intervention of government and service planners.

This section of the report looks at what can be done to make services more person-centred, and how these initiatives could be incorporated into a national cancer strategy for Wales.

## Four key national initiatives

We believe the following four initiatives are essential to making cancer services more person-centred and cost effective.

1. Improved assessment and care planning
2. Reforms to cancer-follow up
3. More personalised information and support
4. Access to an identified key worker

These initiatives are based on our consultations with people living with and after cancer and those working in cancer care in Wales. We also looked at learnings from other chronic conditions and at what is happening in cancer care outside Wales.

### 1. Improved assessment and care planning

People living with and after cancer should have their own treatment and care plan, as well as regular assessments of their clinical and non-clinical needs.

Regular assessments are essential to ensure that treatment and care plans are tailored to each person's needs. They are also vital for establishing risk levels for possible complications or reoccurrence of the cancer. If their condition is incurable, ongoing assessment and care planning are essential to monitor the progression of the disease. That way, the person can live as well as possible for as long as possible.

Tailored and personalised care helps professionals provide support for those most in need, and limit support to those who are willing and able to self-care. This is a more cost-effective way of allocating limited resources.

The assessment and care plan discussion should take place with a health professional who helps to coordinate the person's care (see point four below: Access to a key worker). This will often be a clinical nurse specialist (CNS). They must have the skills and experience to help identify and deal with the person's concerns, up-to-date knowledge of local and national services, and they must know how to refer people to appropriate specialist and non-NHS services if they are needed. The person with cancer should be given a copy of their care plan so they have a record they can refer to.

We want everyone living with cancer to be offered an assessment and care plan at key stages of their cancer journey by the end of the next assembly term.

## 2. Reforms to cancer follow-up

**Follow-up arrangements after initial treatment need to be improved so that every person living with or beyond cancer in Wales gets ongoing support that is tailored to their own level of need and risk.**

Studies show there is considerable potential to improve cancer follow-up arrangements after treatment has finished.<sup>83</sup> And that assessment and care planning are vital to achieve this change.

The current system of face-to-face follow-up with consultants is expensive and often fails to detect reoccurrence. It is also largely ineffective at supporting people who experience the late effects of cancer and its treatment. A recent

## What do assessments and care plans look like?

An **assessment** is a process of gathering and discussing information with the patient and their carer or supporter to understand what the person living with and beyond cancer knows, understands and needs. This holistic assessment is focused on the whole person. Their entire well-being is discussed: physical, emotional, spiritual, mental, social, and environmental. The results are then used to inform their care plan.<sup>1</sup>

The assessment of an individual's needs should include discussion of:

- Physical effects (eg weight loss, problems with appetite, tiredness)
- Lifestyle issues (eg diet, exercise, not smoking)
- Emotional concerns (eg worries about the future, relationships)
- Family matters (eg talking to your family and friends about cancer, worries about genetic risk)
- Job and/or money worries (eg balancing work and treatment, benefits or financial advice, return to work advice)
- Treatment issues (eg concerns about side effects, fertility, risks and benefits of treatment)
- Practical issues (eg sorting out housework or gardening, healthy eating, where to get equipment for the home to make day-to-day tasks easier)
- Spirituality (eg faith, religion or spirituality and any impact this may have on treatment).

A **care plan** is based on the diagnosis and holistic assessment of the person living with or beyond cancer. It prioritises their issues and sets out actions to address them.

The assessment and care plan process ensures that care is consistent with the person's needs. For many this will help facilitate a move toward supported self management.<sup>1</sup>

study of over 1,000 people at 66 UK centres found that 30% reported five moderate or severe unmet needs at the end of treatment. For 60% of these people, these needs had not

### Reforming cancer-follow up in Wales: The Velindre/Macmillan Herceptin Pathways Project

Gill Donovan, a specialist non-medical prescribing breast oncology nurse at Velindre Cancer Centre, has been leading a project since 2009 to reform follow-up arrangements for women with breast cancer who are undergoing Adjuvant Herceptin treatment.

These women face a long treatment pathway, even though most have already had surgery, chemotherapy and, in some cases, radiotherapy. All of these treatments carry side effects, but women receiving herceptin typically feel well and want to regain ownership of their lives. The Herceptin Pathways Project provides telephone follow-up with rapid access to specialist support if needed. This approach promotes flexibility as care is provided closer to home and fewer visits to hospital are needed.

Benefits for the NHS:

- Fewer expensive consultant appointments.
- Clinicians are able to focus their time on more complex cases.
- Cost savings of 17% per patient, amounting to £143,836 if applied to all eligible patients in South East Wales.

Benefits for people living with or beyond cancer:

- Fewer visits to hospital, saving time and money. This can mean five visits instead of 30.
- People are able to get on with their lives following surgery and radiotherapy without having to worry about hospital appointments.
- Support from a specialist nurse via a 24 hour phone line and call-back service.
- 92% of people living with or beyond cancer report that they are extremely satisfied with the new service.

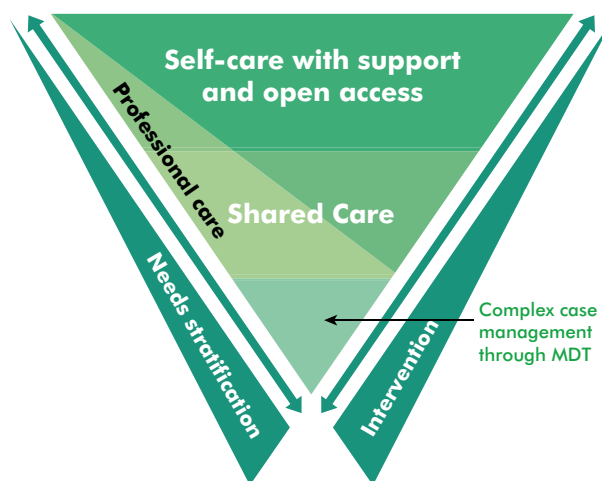
improved six months after treatment.<sup>84</sup>

The late effects of cancer can affect quality of life long after treatment has ended and often leads to unnecessary admittance to hospital as an emergency. With more than 200 different types of cancers and between 30% and 50% of all cancers classed as 'rarer'<sup>85</sup>, many GPs have limited knowledge of the late effects of the disease and its treatment and can't always fully support people in the way they need.

By and large, Wales has a one-size-fits-all approach to follow-up. Regardless of a person's risk of recurring cancer or other complications, most people go through the same follow-up process in the months and years following treatment.

A thorough assessment at the end of a person's treatment makes it possible to develop a follow-up care plan that is tailored to their level of need and risk. Although some routine tests – such as blood tests or imaging – must continue, there is growing evidence that tailoring follow-up care to the individual's needs could make significant savings for the NHS, improve people's experience and outcomes and deliver a better quality of service.

This cancer 'risk stratified model of care'<sup>86</sup> shown below is similar to the approach proposed in the Welsh assembly government's Chronic Conditions Management Strategy<sup>87</sup>:



### Risk Stratified Model of Care

Transformed Care Pathways, NCSI, Department of Health

Experience from the National Cancer Survivorship Initiative (NCSI) suggests that 15-25% of people who survive cancer still require regular face-to-face monitoring or guided

care. And that only 5-10% of them have unmet needs – such as severe and complex consequences of cancer treatment – that require specialist services. Proportions will vary according to tumour type.<sup>88</sup>

For people with complex needs, a reform of follow-up cancer care will give them more contact with health professionals than they have now. For the majority of people with less complex needs who are able to self-manage with support and appropriate surveillance, follow-up reform means they will have less contact with health professionals in the after-treatment phase. Instead, they will need to be

### **What are information pathways and prescriptions?**

**Information pathways** map out the types of information that people living with cancer may want at different stages of their care. Right now, access to information varies across Wales and for different cancer types. Mapping all the information options in one place means it's easy to offer people all the relevant information they might need at that time. The pathways should contain a wealth of information from respected sources on different types of cancer, various treatment options, symptoms and side effects, and the effects cancer or its treatment can have on their life – for example, relationships, sex, finances or work. They should also have information on local support groups and services, and where they can go for further information and support. Information on the pathway should be free of charge, evidence-based, current, culturally sensitive, available in a variety of formats, including the Welsh language, and through a variety of channels.

**Information prescriptions** are a written copy of the conversation between a cancer professional and the person living with or beyond cancer about the patient's information needs. The professional uses the pathway to frame the conversation and offers information that's relevant at that time. The person can then read what they have been told, and be referred to more sources of support.

given information about signs and symptoms and who to contact.

Any work to change follow-up beyond initial treatment would need strong clinical leadership to take forward.

Macmillan wants every person living with or beyond cancer in Wales to receive follow-up care that is tailored to their needs by the end of the next assembly term.

### **3. More personalised information and support**

**Every cancer patient in Wales should be offered tailored information and support throughout their cancer journey.**

To make services truly person-centred, people living with and after cancer need to be at the heart of decisions made about their treatment and care. Providing personalised information and support is essential. This means more than handing someone a leaflet about their cancer. It involves selecting short sections of information that answer their needs and the stage of their cancer journey. We believe that information pathways and prescriptions should be developed to make personalised information and support a reality in Wales.

By building information pathways and prescriptions into cancer care we can ensure that high quality information is offered to people at key points in their cancer journey, as well as the support they need to understand and act on what they've learned.

We know that giving people personalised information and support, and helping them to self-manage, leads to better outcomes for long-term chronic conditions<sup>89</sup>, including cancer. When people are well informed they know what to look out for and what to do to manage their signs and symptoms. If they know what to expect, they worry less, are less likely to seek advice from emergency services and can resolve problems without professional intervention.<sup>90</sup>

Many of the support services that people living with and after cancer need already exist, and are often provided by the voluntary sector. Now Wales needs the provision of information and support built into its new strategy so that it becomes an integral part of the care pathway.



## **Our information and support**

How we are helping with the development of information and support for people living with and after cancer in Wales:

### **1. Macmillan all-Wales Cancer Information Project**

#### **Phase 1: All-Wales Cancer Information Pathway Project**

The project carried out an in-depth review to see what information is being offered to cancer patients, their carers and families across Wales. The review included mapping the source, format and languages in which information is provided. Using these findings draft information pathways were developed for key cancer sites including breast, urology, gynaecology, colorectal, lung and upper GI. These pathways will be finalised after consultation. In the meantime, discussions are ongoing to source an online storage facility so the pathways can be accessed by health professionals across Wales.

#### **Phase 2: Macmillan Cancer Information Strategy Lead (Wales)**

Macmillan Wales is investing in a cancer information strategy post, which will be hosted by Public Health Wales. The post will help improve the coordination and delivery of information to people living with and after cancer across Wales. It will also assess whether the cancer information

model can be transferred to other chronic conditions.

### **2. Macmillan cancer information and support centres and coordinators**

In 2008, we began a programme of investment to improve access to information and support. We worked in partnership with the NHS and other voluntary sector organisations to open Macmillan cancer information and support centres in Wrexham and Llandrindod Wells. We are also working with Welsh local authorities to develop cancer information and support in local libraries, and we fund Macmillan information and support coordinators to manage our centres and library presence. Our coordinators work alongside volunteers to deliver a comprehensive service for local people.

### **3. Access to cancer information and support at home**

Since we merged with the cancer information charity, Cancerbackup, in 2008 we have been able to offer a wider range of high quality information and support resources for people living with and after cancer. Some of our most requested titles are now also available in Welsh. We produce free and comprehensive cancer information and support, as well as access to information on our website, and a free phone service on 0808 808 00 00.

We want every cancer patient in Wales to be offered information and support throughout their cancer journey by the end of the next assembly term.

### **4. Access to an identified key worker**

**Every cancer patient should have access to a named key worker who understands their needs and is able to support them during and after treatment.**

In May 2010 the government announced that all people with a cancer diagnosis in Wales would be given a key worker to coordinate their care.<sup>91</sup> The new Local Health Boards were required to implement the policy by March 2011. We warmly welcomed this

announcement. We understand the work has begun, but as yet there is no nationally agreed, clear definition of the key worker role. And most planning for the scope and function of the key worker role in Wales is being undertaken locally. This may lead to inconsistency and geographical inequality in the level and quality of service provided.

We believe it is important that the implementation of the key worker initiative in Wales is consistent. Although key workers may be different professionals at different stages in a person's cancer journey, there should be consistency in their functions and responsibilities throughout Wales. With the current approach there's a risk that the type of key worker a person has to support them will

depend on where they live rather than on their needs and circumstances.

In developing the role of the key worker, it is vitally important to consider continuity of care. Issues such as access to key workers out of hours, the transition from secondary to primary care and the use of electronic records are all essential to the success of this initiative.

In order to ensure consistency across Wales, the role and remit of a key worker must be agreed at a national level by the end of the first year of the next assembly term. By the end of the second year of the next assembly term, we want every person living with or beyond cancer in Wales to have access to a relevant, named key worker.



### **What is a key worker?**

#### **What should a key worker do?**

Based on our research , and work carried out by governments elsewhere in the UK , the role of the key worker is to:

- Be a main point of contact.
- Undertake assessments, agree care plans and ensure the details of the care plan are communicated to the person living with cancer and others involved in their care.
- Be ultimately responsible for coordinating care and managing care transitions.
- Provide information about cancer treatment and its effects. Help the person living with and after cancer to understand that information so they can make informed decisions.
- Find out what additional help and support the person needs and make sure they get it. This may mean signposting them to other support services, such as financial advice, practical help and emotional support. Ensure people know who to contact when they have questions or need help.
- Give advice to the person and their carers.

It should be acknowledged that the implementation and coordination of a person's care may be carried out by a number of clinical and non-clinical professionals.

#### **Who will they be?**

During the treatment phase, the key worker is likely to be the clinical nurse specialist. After treatment, the most appropriate key worker will depend on the type, severity and advancement of the cancer and the needs of the person. For people living with and after cancer who have complex needs, their key worker is likely to be very involved. For those who have moderate needs, their key worker will be less involved. For people who have no complex needs, they are likely to have more limited contact with their key worker, although the key worker should be available if any issues arise. The important thing is that the person living with and beyond cancer knows who their key worker is, and the key worker knows their responsibilities to that person.

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Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial help and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

Questions about living with cancer?  
Call the Macmillan Support Line free  
On 0808 808 00 00  
(Monday-Friday 9am-9pm).

Alternatively, visit [macmillan.org.uk](http://macmillan.org.uk)  
Hard of hearing? Use textphone  
0808 808 0121, or Text Relay.

Non-English speaker?  
Interpreters available.

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