

**HAVING
YOUR SAY
ABOUT CANCER
IN WALES**

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CANCER SUPPORT**

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People affected by cancer highlight the gaps in cancer services in Wales

This report was drafted between November 2008 and June 2009. The report author is Jennifer Mitchell, Macmillan Cancer Support Policy Analyst.

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- The patient survey respondents
- TwoCan Associates
- Attendees at the Macmillan Have Your Say conference
- Macmillan's User Involvement Steering Group for Wales

If you would like to comment on the report, or for more information about Macmillan's policy, public affairs and campaigning work in Wales, please contact Gwenllian Griffiths, External Affairs Manager for Wales on ggriffiths@macmillan.org.uk or call 01656 867960.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. For more information about Macmillan please go to www.macmillan.org.uk. If you have concerns or questions about living with cancer, please call the Macmillan Cancerline on 0808 808 2020.

Macmillan Cancer Support: having your say about cancer in Wales

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Executive Summary

1. Macmillan Cancer Support has undertaken listening exercises with people with cancer from Wales to determine the gaps which exist in support services. This work took the form of a cancer patient survey to identify where problems lie and a conference of people with cancer to explore potential solutions.
2. The greatest need people with cancer face is practical help, although the majority of those surveyed said this need had been met with the help of friends and family. The greatest unmet needs were emotional support, employment support and financial support. Many people with cancer do not seem to be getting information about the support they need or told where they can go for help. Many respondents commented on the ongoing need for support once treatment has finished.
3. People with cancer agreed that many of the support services required were already available but that they were poorly promoted or patients felt too unwell to navigate the system to find them. It was also agreed that lots of information is available but it can be overwhelming and untailored to the needs of the individual person with cancer. Information was available from many places, duplicated and not necessarily kept up-to-date.
4. The recurrent solutions proposed to ensure that the needs of people with cancer are met, were a key worker, increased promotion of services, improved awareness of the needs of people with cancer among health professionals and more relevant and targeted information.
5. Macmillan will work with the Welsh Assembly Government, the Cancer Services Coordinating Group and the Cancer Networks, to examine each of these solutions and address the underlying problems in the system which they highlight: the poor integration and coordination of services, difficulty accessing services and lack of information and support.
6. Many of these problems are already beginning to be addressed by Macmillan and Welsh Assembly Government supported initiatives: development of a cancer rehabilitation standard, assessment of the needs of cancer survivors, development of a Wales Information Strategy and roll out of Macmillan Information and Resources Centres and Facilitators.
7. Macmillan will also look to promote awareness of the unmet needs of people with cancer among health professionals and will continue to develop its supportive care model, Macmillan Solutions.

Introduction

Cancer is the second most common cause of death in Wales. Wales has an older population compared to the rest of the UK (17.6% of the population are aged 65 and over) and over 17,700¹ new cases of malignant cancer and 8748 deaths from cancer were registered in Wales in 2007². The commonest cancers were lung, skin, breast, colorectal and prostate, accounting for over half of all new cases³. Wales has the highest death rates for cervical cancer, female breast cancer and prostate cancer and the highest rates of newly diagnosed cases of female breast cancer and prostate cancer.

However, more and more people are living longer with cancer as survival rates continue to improve. There are now more than 116,000⁴ people living with or beyond cancer in Wales and 4% of the population aged 16 and over has been treated for cancer. The number of people living with cancer will increase further over the next decade and with advances in treatment, more will be living longer with secondary cancer. The Wales Cancer Intelligence and Surveillance Unit has projected that by 2012, the number will have increased to 157,000. These patients often experience long term effects of treatment. They require specific health and social care support to help them cope with these effects.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. There are more than 200 Macmillan professionals helping people affected by cancer in Wales. We fund a variety of health and social care posts including: Welfare Benefits Advisers; Clinical Nurse Specialists; Dieticians; Occupational Therapists; GPs; Specialist Physiotherapists; User Involvement Facilitators and Specialist Social Workers. In 2007 and 2008 Macmillan invested a record £4.9 million pounds in health and social care posts and services across the NHS, Local Authorities and other voluntary organisations in Wales.

Macmillan is a force for change, listening to people affected by cancer and working together to improve cancer care. People who live with cancer are experts by experience. They are a powerful resource; telling us what is needed and what must change. Together we can use this knowledge to make a positive difference to the lives of people affected by cancer. The patient voice needs to be heard at all stages in the design, implementation and evaluation of cancer services.

Macmillan Cancer Support is aware that people with cancer in Wales, although generally very happy with the clinical care they receive, do not feel they are receiving the emotional, practical and financial support and information they require. Throughout 2007 and 2008 Macmillan undertook a piece of work to identify the unmet needs of patients and potentially some solutions for how these needs could be met. This report discusses the findings.

¹ <http://www.wales.nhs.uk/sites3/home.cfm?orgid=242>

² Health Statistics for Wales 2007

³ http://publications.cancerresearchuk.org/WebRoot/crukstoredb/CRUK_PDFs/incidence/cs_inc_t8.3.xls

⁴ Wales Cancer Intelligence and Surveillance Unit, Triennial Report
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=33893>

Section 1: Patient survey

Background

Macmillan commissioned a survey of cancer patients in Wales⁵ to explore their practical, social and emotional needs; rather than their experience of clinical treatment. The aims of this project were to find out:

- About people's broader experience of having cancer and receiving support.
- Whether the findings from an initial consultation of small group of service users and carers match with a wider population.
- If users and carers have other issues that have not yet been identified in Macmillan's consultation work to date.

Methodology

The Steering Group for this project included Macmillan staff and people affected by cancer in Wales. They decided to carry out an initial consultation with people affected by cancer to determine the scope of the survey. The conclusions were that the survey should focus on people's practical, social and emotional needs, rather than their experience of clinical treatment.

TwoCan Associates worked with the Steering Group to develop the questionnaire. A draft version was piloted with 10 people affected by cancer from local support groups. The draft questionnaire was then revised to include their comments and piloted once again with a wider group of service users.

The final version of the questionnaire was printed in English and Welsh and 750 copies given to the three Cancer Centres in Wales (250 copies to each centre). They agreed to send the questionnaire to 250 of their cancer patients who had been diagnosed between September and November 2006. The aim was to capture the views of people with different types of cancer, who had experience of different stages of the cancer journey.

Macmillan provided the Cancer Centres with stamped, sealed, blank envelopes containing:

- a cover letter
- the questionnaire
- a freepost envelope to return the questionnaire to Macmillan
- a postcard that people could choose to send back separately - either to register their interest in receiving a copy of the final report and/or their willingness to be involved in other Macmillan projects.

The Cancer Centre staff added the names and addresses of their patients to the envelopes and posted the questionnaires. In this way the confidentiality of people's personal details were maintained.

⁵ Listening to the priorities of people affected by cancer in Wales – results from a pilot survey, Macmillan Cancer Support and TwoCan Associates, April 2008

The Cancer Centre staff also checked the patient records to ensure that questionnaires were not sent to people who were actively receiving treatment or to people who had died, so as to avoid causing anyone further distress.

The survey respondents were asked to return the questionnaire within three weeks of posting. A total of 168 questionnaires were returned. This represents a minimum response rate of 22% (assuming all 750 questionnaires were posted).

Results

Respondents

168 people responded to and completed the survey. 58% of respondees were from people who had had treatment at the Cancer Centre in South East Wales, 4% from people treated at the Cancer Centre in North Wales and 36% from people treated at the Cancer Centre in South West Wales.

The respondents had been affected by a wide range of cancers. In line with general incidence rates, the majority had been diagnosed with breast cancer, bowel cancer or prostate cancer:

Type of cancer	% of respondents diagnosed with this type of cancer
Breast	36%
Bowel	17%
Prostate	11%
Lymphoma	8%
Ovarian	5%
Endometrial	4%
Liver	4%
Mouth	2%
Lung	2%
Oesophagus	1%
Pancreas	1%
Kidney	1%
Cervical	1%
Bladder	1%
Throat	1%
Melanoma	<1%
Testicular	<1%
Head	<1%
Stomach	<1%
Leukaemia	<1%
Papillary	<1%
Sinus	<1%
Thyroid	<1%
Thyromal tumour	<1%

70% of the respondents were diagnosed with cancer between September and November 2006. The remainder were diagnosed sometime between October 1998 and November 2007.

32% of the respondents were male and 63% were female. The respondent came from a wide age range but 78% were aged between 46 and 75:

Age range	% of respondents in this age range
18-25	<1%
26-35	2%
36-45	6%
46-55	20%
56-65	25%
66-75	33%
76-85	10%
86-95	<1%
95+	0%

64% of the respondents came from urban areas and 32% from rural areas. 98% of respondents identified themselves as White British.

The survey explored six areas of people's practical, social and emotional needs:

- Practical help with daily living
- Counselling
- Financial support
- Employment
- Support from other patients and carers
- Gaps in information and support

The main finding from each section are summarised in the next section of this report.

1. Practical help with daily living

43% of the respondents said they had wanted practical help while they had cancer. The people who had wanted practical help said the kind of help they had needed was help with:

Respondents wanted help with:	% of respondents who wanted this kind of help
Shopping	58%
Housework	43%
Cooking	19%
Childcare/school runs	14%
Bathing/showering	14%
Getting to appointments	14%
Day to day care	8%
Travel by car	8%
Lifting things	6%
Dressing	6%
Going up & down stairs	3%
Walking	3%
Care for a partner	3%
Going to the toilet	3%
Dog walking	1%
Gardening	1%

Many people said this kind of practical help had been provided by friends and family.

Person providing practical help	% of respondents who mentioned receiving help from this person
Partner	28%
Daughters/ sons	15%
Friends	4%
Sister/brother	3%
Neighbours	3%
Mother/father	3%

But some respondents felt this had imposed a cost to their family and friends; for example they had to take time off work.

The wife had to finish work to help me due to having problems with getting time off.

Of the 43% of people who said they had wanted practical help, **81%** reported that they had received the help they needed and **11%** said they had **not** received the help they needed. Some people were offered extra help and those that had used support services did find them helpful.

49% of the respondents were **not** told where they could find practical help. **10%** could not remember whether they had been told about where they could find practical help. Some people felt they had had to seek out this kind of support for themselves rather than being offered help automatically.

I think the information was there if you needed it or if you took the trouble to look for it.

2. Counselling

20% of the respondents said they had wanted counselling while they had cancer but only **43%** of the respondents were told about where they could get counselling. Of the people who said they had wanted counselling, **45%** reported that they had not received this support.

20% of all the respondents had a partner or family member who had needed emotional support. Of the people who did have a family member needing emotional support, only a third (**33%**) were offered counselling.

Many respondents said they had relied on friends and family for emotional support. Some people said they now know they had needed emotional support while they had cancer, but were not aware of this at the time.

In hindsight I probably did need support but wasn't aware of it at the time - emotional needs weren't discussed with the nurses doing consultations, I think they were too busy.

Some people did receive information about counselling services, although this was not always appropriate and some people thought they could still benefit from counselling some time after their treatment.

I don't honestly remember being told where I could get counselling but there were always lots of notices, etc.

3. Financial support

24% of the respondents had wanted information and support to help manage their financial situation and **67%** had **not** wanted this type of support. The people who had wanted financial support said they needed help with the following:

Respondents wanted help with:	% of respondents who said they needed this kind of information/ support
Managing reduced income	35%
Accessing benefits	78%
Pensions	15%
Insurance	33%
Mortgages and rents	18%
Transport costs	38%
Grants from charities	25%

Of the people who said they had wanted financial information and support, **65%** had received the information/ support they needed while **30%** had **not** received any information or support. Of the people who said they had wanted financial information and support, **58%** were told where to get the information/support they needed.

Some respondents commented on the lack of information about financial issues and others that they had received financial information but either after some delay or not until it was too late.

The information I received was "piecemeal" and late. I actually had to go onto 1/2 pay for 3-4 months which left me with debt. Thank God I never had debt before I was ill so therefore this was manageable but still upsetting. This was the area I had least support provided.

Some people found the process of applying for benefits difficult and some people had benefited from professional help or had managed the process themselves. Some people commented on how they continue to need financial support and advice, some time after their treatment.

It is only now I require help as pay from work has stopped after 1 year off work.

4. Employment support

13% of the respondents said they had needed information/support to help manage their work. The people who had wanted support relating to their employment said they had needed help with the following:

Respondents wanted help with:	% of respondents who said they needed this kind of information/ support
Managing work while receiving treatment	23%
Information for employers about cancer	23%
Negotiating changes to employment contracts	27%
Managing a return to work	64%
Ending work	14%

55% of respondents had been told about where to get information and support relating to employment, while **36%** had *not* received this information. Of the people who said they had wanted information and support relating to employment, only **27%** had been told where to get the information/support they needed.

Amongst the respondents who were working age, 42% were not aware of their rights under the Disability Discrimination Act.

Some people who said they had experienced problems in managing a return to work, had returned to work too soon because of financial problems.

When returning to work I was still ill. Employers expected too much too soon and docked my wages when I could not attend which meant there was little point in struggling to work.

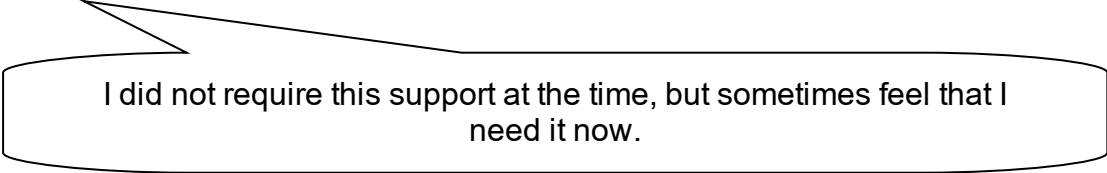
Some people had received helpful support and advice via their employers, most noticeably within the NHS and some people said they could still benefit from employment advice.

5. Support from other patients and carers

36% of the respondents said they had wanted support and advice from other patients and carers. Of these, **75%** had received the advice/support they needed, whereas **23%** had *not*.

36% of respondents had been told where they could get advice/support from other patients and carers but of the people who said they had wanted this type of support only **54%** had been given information about this.

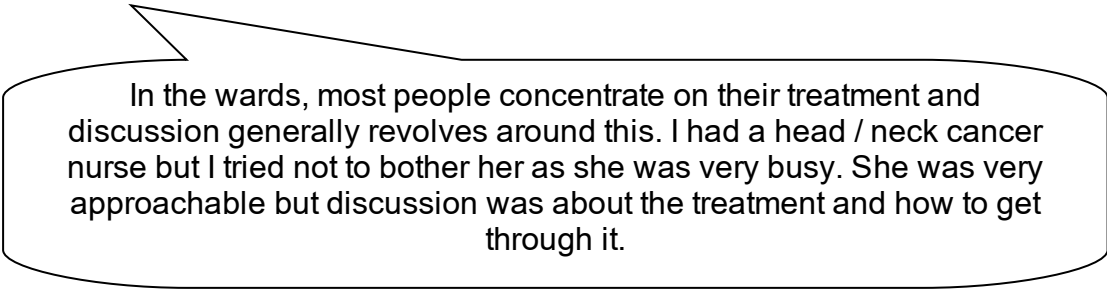
Some people felt they did not need this kind of support as they were supported by family and friends. Some people found this support for themselves and had found it very useful. Some people would still like to find this kind of support:



I did not require this support at the time, but sometimes feel that I need it now.

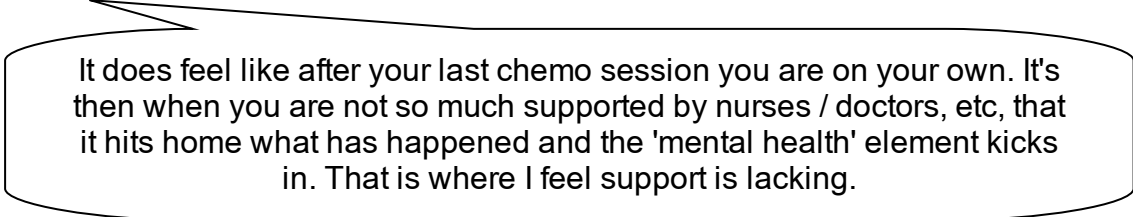
6. Perceived gaps in information and support

Some respondents commented on the lack of support available in hospital, mainly because health professionals are too busy, lack capacity and everyone is focused on the clinical care.



In the wards, most people concentrate on their treatment and discussion generally revolves around this. I had a head / neck cancer nurse but I tried not to bother her as she was very busy. She was very approachable but discussion was about the treatment and how to get through it.

Some people also identified the need for more support at the time of diagnosis and others identified the 'end of treatment' as the most significant point when more support is needed.

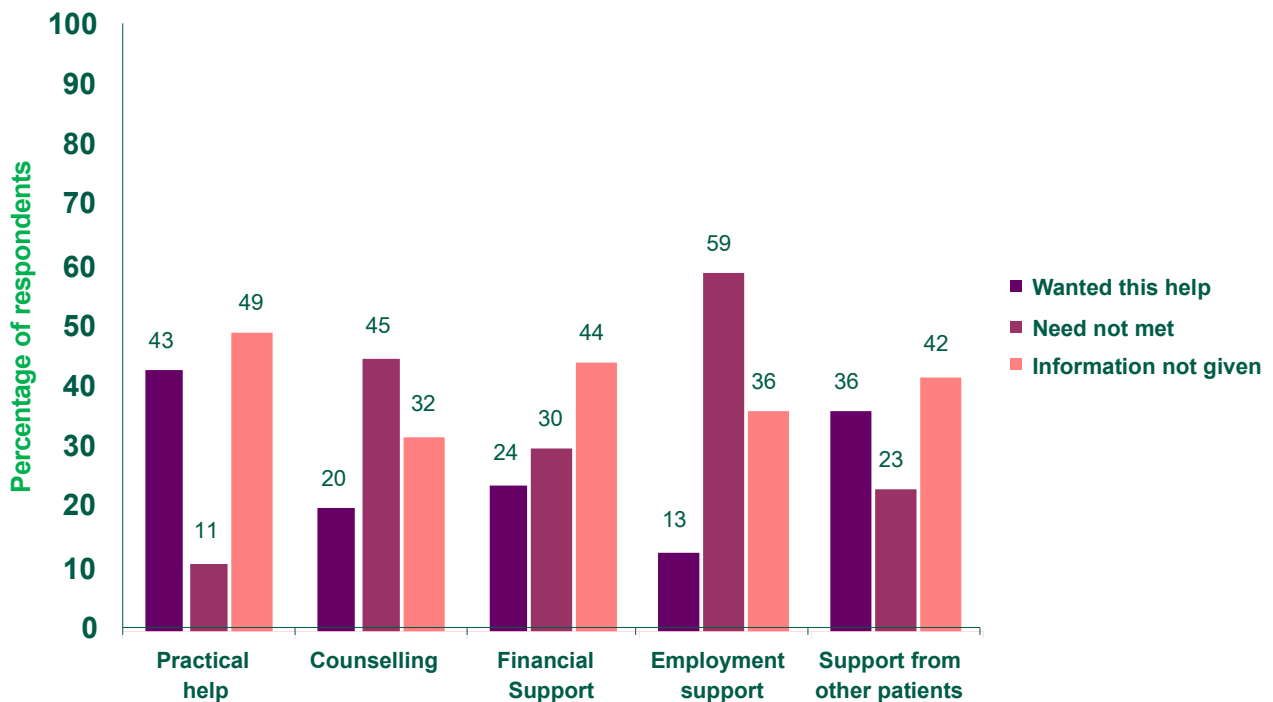


It does feel like after your last chemo session you are on your own. It's then when you are not so much supported by nurses / doctors, etc, that it hits home what has happened and the 'mental health' element kicks in. That is where I feel support is lacking.

In terms of the type of support available, respondents most often commented on the lack of financial support but others commented on the lack of counselling and also recommended that this be provided over a longer period.

Conclusion

It is clear from the findings that people living with cancer have a range of different needs throughout their cancer journey. However, many are not getting the support they need and are not given information about where and how they can access support. The greatest need was practical help – although respondents were happy to receive this help from family and friends and not necessarily professional carers and 81% said this need had been met.



However, of those people with cancer whose needs were not being met, the greatest unmet needs were emotional support, employment support and financial support. Many respondents commented on the need for support once treatment has finished as they continue to have ongoing requirements long after treatment ends. This is often when people find themselves 'out of the system' and without the relevant information necessary to find the help and support they need.

Further considerations

The response rate from the different Cancer Centres was so variable that it was not possible to make a meaningful comparison across the centres. The respondents to the survey were quite diverse in terms of their cancer type and age. They also included a reasonable mix of men and women and of people living in urban and rural areas. An obvious gap is the lack of responses from people in black and ethnic minority (BME) groups. This is consistent with findings from other surveys conducted by national patient organisations. A different approach is needed to find out about the experiences of people affected by cancer from more diverse communities.

Section 2: Have Your Say conference

Background

Macmillan Cancer Support holds an annual conference for people living with or beyond cancer from throughout Wales. Many of the conference attendees are members of user involvement groups at their various cancer networks or help to run self help and support groups for people with cancer in their local communities. All have been touched by cancer; either as patients or carers. The conference is an opportunity to share their experience and expertise to influence Macmillan's work and to network and exchange best practice.

This year Macmillan decided to alter the focus of the conference. Having gathered evidence on the main problems people living with and beyond cancer were facing with regards to their ongoing support needs, Macmillan wanted to use the expertise of those gathered to explore potential solutions and ways of ensuring those needs were met.

Conference format

After an introduction and scene setting from the General Manager of Wales at Macmillan, Cath Lindley, the conference broke out into four workshops each focusing on one of the main unmet needs identified by Macmillan: emotional, practical, employment and information support. The workshops were repeated in the afternoon and the key finding or idea was reported back to the conference by the workshop facilitator at the end of the day.

Each workshop was led by a facilitator and began with a short talk by a professional or Macmillan staff member on the relevant area of support (i.e. emotional, practical, employment or information issues). Workshop attendants then broke out into small groups of twos or threes to discuss ideas before rejoining the group as a whole to discuss these and any other ideas together. As far as was possible, all ideas were recorded and are included in Appendix One.

Workshop findings

1. Employment support

It is estimated that more than 43,000 people of working age are living with or beyond cancer in Wales. For many people with cancer getting back to work is like getting back to normal – it is often a person's personal goal for getting through treatment. It has been estimated that about 62% of people diagnosed with cancer are able to return to work.

However, Macmillan has identified several problems people face getting back to work:

- People are returning to work with no information or advice.
- Occupational health provision is patchy and not geared to post treatment.
- Half of people with cancer were not informed by their employers of their statutory rights.
- Only one in five employers are aware that cancer is included in the Disability Discrimination Act (DDA).

Workshop conclusion:

Solutions and improvements proposed in the workshop broadly fell into the main categories outlined below. For a full list of all the ideas proposed, please see Appendix One.

- Improve the awareness among employers, employees and advisers of the problems people with cancer face when returning to work and of their employment rights.
- Provide those returning to work with a holistic assessment given by an appropriate practitioner to inform the process of returning to work and signpost to appropriate services and information.
- Support the person with cancer through the process of returning to work after cancer. Many forms of support were suggested; for example careers advice, rehabilitation and retraining, help filling out forms, etc. A key worker or advocate could be available to coordinate all the services the person with cancer requires.
- Encourage employers to adopt a clear HR policy on sickness and absence for people affected by cancer and a process through which grievances can be resolved.

2. Emotional support

It would be nice if when being told you have cancer you are also informed of emotional services to access ... because you need to learn how to fight this thing because you are likely to be thinking I'm going to die.

People with cancer and their carers sometimes require somebody to talk to about their emotions outside their immediate family or friendship group. There are three key stages in the patient journey where a person with cancer may require emotional support:

1. At diagnosis
2. During treatment
3. At the end of/following treatment.

However, patients have reported ongoing difficulties trying to persuade professionals, especially GPs, to refer them to self help and support groups and have also reported that emotional support is mainly provided in a one size fits all format rather than tailored to the individual.

The nurse said to me: "you can have social services – they can clean for you" but this was not what we needed – our needs were so poorly understood by the medical and nursing profession.

Workshop conclusion:

Solutions and improvements proposed in the workshop broadly fell into the main categories outlined below. For a full list of all the ideas proposed, please see appendix one.

- Better coordination of care from diagnosis onwards. This could be provided by a named key worker - someone to champion the person with cancer's needs and act as an advocate. It was felt that this didn't have to be a nurse but it does need to be someone who understands cancer.
- Learning and development to raise awareness of the emotional needs of patients among health professionals and training for professionals, patients and carers to equip them to cope with emotions.
- Provide patients with access to a warm and welcoming environment where they feel at ease to open up and share emotions. This should be away from the clinical area.
- Easy-to-access support at all times. Services must be relevant and inclusive to the communities they serve for example special consideration is needed for those aged over 70, people from marginalised communities, those with learning difficulties and those from the BME community.

3. Practical support

Politicians need to be aware of the huge financial implications to the health service of not providing patients and carers with adequate practical support

People with cancer have a whole range of practical support needs, from childcare to transport, pain management to DIY tasks. People with cancer don't just require 'signposting' to services – they need the practical support to be there when it is required. There is a disconnection between health and social care services which often means that the low to moderate needs of cancer survivors are neglected. There is also a shortage of allied health professionals able to provide the support needed.

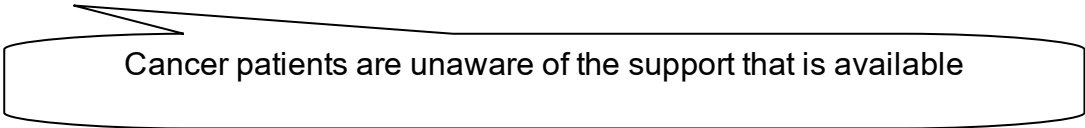
My mother was very independent and always told officials she was coping and fine, when in reality she needed help. I was able to attend the meeting with the social worker and took on the role as her advocate.

Workshop conclusion:

Solutions and improvements proposed in the workshop broadly fell into the main categories outlined below. For a full list of all the ideas proposed, please see appendix one.

- Assessment of patients at key points along the pathway to identify the support they may require.
- A wide range of practical support including a patient advocate who could guide and signpost patients to services such as home and garden maintenance and repair, child care and transport.
- Better promotion of the services available which could be achieved in a number of ways including personalised patient information and using community hubs and GPs.
- Improved education amongst health professionals about the support that patients may need and how it can be accessed.

4. Information



Cancer patients are unaware of the support that is available

People with cancer say they need information on all sorts of issues and not just medical information. People with cancer can feel overloaded with information when they are first diagnosed and then forget what they have been told. For example 70% of patients say they were not given welfare advice and yet their nurse said that they were given this information. Information may also be duplicated or out of date. People with cancer have told Macmillan that written information is not always adequate and that sometimes they would prefer a face-to-face discussion.



You don't know what you don't know

Workshop conclusions:

Solutions and improvements proposed in the workshop broadly fell into the main categories outlined below. For a full list of all the ideas proposed, please see appendix one.

- A key worker or buddy to give information at the relevant points along the patient's journey and to act as someone who can be contacted with questions.
- Information that is relevant, current, regularly updated, targeted not general, and available in a variety of formats. It must cover a wide range of topics including treatment, nutrition, benefits/ financial issues, employment, sexual function and fertility, emotional support, travel, complementary medicine and after care.
- A file for patients of all the needed information including names of key carers, diagnostic and treatment results, cancer specific information, treatment information, etc.
- A central, national information service which could be delivered locally for example through information centres, libraries, etc._
- Better promotion of information resources at medical centres and by healthcare professionals.
- More communication training for professionals particularly on patient friendly language and empathy.
- An information manager at each hospital - someone who is responsible for giving the patient information.

5. Overall workshop conclusions: key themes

Workshops appeared to agree that many of the support services required were already available but that they were poorly promoted or patients felt too unwell to navigate the system to find them. It was also agreed that lots of information is available but it can be overwhelming and untailored to the needs of the individual person with cancer. Information was available from many places, duplicated and not necessarily kept up-to-date.

In overcoming these key issues, all workshops returned to the following four themes:

1. A key worker or navigator role
2. Increased promotion of services
3. Improved awareness of the needs of people with cancer among health professionals
4. More relevant and targeted information.

It was suggested that a key worker or buddy could help guide the patient through their journey and through the system; signposting to services and support, providing information and answering questions. Groups agreed that the key worker or buddy should be assigned at the point of diagnosis and should be available for the patient to contact during and after treatment, for example, when they are returning to work or dealing with the late effects of treatment. Such a key worker or buddy would ensure the person with cancer was not overwhelmed with information but given what they required when they required it and given information relevant to their circumstances.

The perceived need for a key worker demonstrates the difficulties patients face trying to navigate through a complex system and highlights several important underlying issues with the current system: the poor integration and coordination of services, difficulty accessing services and lack of information and support. If each of these important parts of the patient experience were addressed individually, many of the needs of people with cancer would be met and the problems which they face erased.

There was agreement that information needed to be collated into a central resource for people with cancer. This information resource would cover information on support needs as well as medical and treatment details and should include localised services.

Section 3: Macmillan's recommendations

Addressing cancer patients' needs

In Appendix 2 we have taken each of the underlying problems identified in this report and mapped current initiatives by Macmillan and the Welsh Assembly Government, the Cancer Services Coordinating Group (CSCG) and the Cancer Networks, to improve these areas as well as suggesting future work.

It will be important to monitor progress to ensure that these initiatives are improving the experience of cancer patients. This could be achieved by the development of a regular Wales cancer patient experience survey (as proposed in *Designed To Tackle Cancer in Wales 2008-2011*) but it will need to be carefully designed to ensure that it measures aspects of the patient journey of importance to the overall patient experience.

1. Navigation

In late 2005 Macmillan undertook a scoping study to examine the evidence around the structure and benefits of providing a 'navigator' for people with cancer. A 'navigator' is an American role which has been piloted by the NHS in England and is almost identical to the key worker role proposed at the Have Your Say conference.

The study questioned whether navigation should be integrated within existing job roles or a job role in itself. It highlighted the overlap between a potential navigator role and current existing roles and the potential advantages and disadvantages of giving this role to a professional, nurse, administrator or lay person. The study concluded that a navigator should promote choice, be culturally appropriate and ensure a continual relationship.

- **Macmillan will need to give this issue further thought and will need to examine whether the key worker role identified within the draft Cancer Rehabilitation Standards for Wales will address many of the underlying problems highlighted in this report.**
- **Further consideration is required to establish whether the 'navigator' role is required if integration, coordination, access and information were addressed.**

2. Information

The patient survey clearly demonstrated that patients aren't receiving the right information at the right time about the services available to meet their needs. Attendants at the *Have Your Say* conference agreed that information was often available if you sought it but that it was often overwhelming, irrelevant and out of date. A more methodical and easy to access information system is required. Many of the problems people with cancer face could be solved if they had the information to help them.

A common and quality assured approach should be taken to provision across Wales. Macmillan is funding an All Wales Information Development Manager post within the

North Wales Cancer Network to develop a Cancer Information Strategy for Wales. The project involves mapping information pathways - key points along the patient journey at which certain pieces of information or support may be required. The project is currently drawing together information sources to make them available electronically in one place for health professionals to access. Macmillan will use experience gained from other nations such as England where we are helping the Department of Health to develop information prescriptions.

- **Macmillan recommends that the Welsh Assembly Government commits to a common and quality assured approach to information provision for cancer patients in Wales. For this to be achieved Wales needs a patient information strategy that is fully funded.**

Macmillan has also begun to fund and develop Cancer Information and Support Centres and Cancer Resource and Information Facilitators in Wales. In 2009 we opened the Macmillan Shooting Star Information Centre in Ysbyty Maelor Wrexham, and work is about to start to build a Cancer Centre at the Bracken Trust in Llandrindod Wells for people affected by cancer in Powys.

The information centres, which already exist in England, will act as information hubs; providing information on financial, emotional and other support. People with cancer will be able to drop in to the centre, email or telephone.

- **Macmillan will continue to explore opportunities to develop Information and Support Centres and Cancer Resource and Information Facilitators and volunteers to provide a more tailored and relevant information service to people with cancer in Wales. This will involve looking to work creatively with partner organisations to help us provide information via in already existing centres such as libraries and hospital foyers.**

3. Macmillan solutions

Macmillan is currently undertaking two pilot projects in England delivering social care support to people with cancer via volunteers. Depending on the outcome of these pilots, we hope to roll out these models to the whole of the UK, including Wales, in the near future. If successful this Macmillan project will help to meet many of the identified unmet practical needs of people with cancer as well as helping to inform and signpost people to the help available.

The Macmillan Solutions service is best described as an umbrella of available support for anyone affected by cancer, promoting an experience that promotes independence and choice. The key elements of the umbrella of support are:

- **Narrative assessment:** This is a user-focused method in which people tell their personal story and with support identify the services and opportunities they want and what is available locally under the Macmillan Solutions umbrella. The volunteer advocate may then suggest a number of support mechanisms
- **Buddy:** The need for one-to-one emotional support from a cancer buddy may be identified, in which case Macmillan Solutions can match individual buddy volunteers to people looking for support
- **Information:** Macmillan Solutions will be supported by a database of easily accessible local information to help signpost people.

- **Individual budgets:** Narrative assessments may conclude that a particular service user needs a personal Macmillan Solutions budget, available to them directly in the form of vouchers, a credit card or cash. It would be spent by the individual on whatever they have identified would improve their own sense of well-being. This might include buying a service that they would not generally be entitled to, overcoming a particular financial hardship, a treat that would improve their quality of life or buying a gift to thank a friend.
- **Skill swaps:** Skill swaps are an integral part of Macmillan Solutions, addressing the problem that – while many people during their cancer journey value the support they receive – there are relatively few opportunities or invitations to give back or to support others.

4. Educating professionals

Increasing awareness and understanding among professionals of the practical, emotional, financial and information support needs of people with cancer will be key if these are to be met. This will include promoting the importance of support groups and self-management programmes in helping address these needs. Macmillan will look for ways to raise this awareness.

Macmillan provides learning and development support to Macmillan-funded professionals working in the NHS, social and advice services. Macmillan will consider how existing programmes could be revised to promote the unmet needs of cancer patients more strongly, as well as considering whether additional programmes should be introduced.

- **Macmillan will review existing Learning and Development programmes to identify opportunities to raise awareness and increase understanding around the needs of people with cancer.**

Appendix 1:

Full list of workshop ideas

1. Employment support

Group discussion

1. Problems with the existing system:

- There is prejudice against people with cancer among employers
- People who choose to return to work part-time lose pay and future pension
- Experience is very much dependent on the individual and their work place – are they valued, side lined etc

2. Possible solutions/improvements:

- Awareness:
 - Employers and employees should be educated about their rights - patients should be made aware of their employment rights and given information on the legalities, benefits process and entitlements.
 - Employers should be made aware of the needs and problems (both emotional and practical) of people with cancer returning to work – Human Resource (HR) departments in the private and public sector should be educated (through face to face education, literature or DVDs) about people's rights and that cancer is a long term condition.
 - The person with cancer should be given a checklist, DVD and DDA information which they can give to their employer; including what the employer can reasonably expect from their employee. The person with cancer will require support to do this.
 - Information should be given to carers on their employment rights.
 - Job centre staff should be educated
- Support:
 - A key worker (not necessarily a medical professional) should be identified to provide advocacy and support around employment issues to the patient.
 - The support needed to return to work from the patient's point of view should be identified.
 - Litigation assistance should be provided
 - Formal or informal individual and holistic assessment by an appropriate practitioner prior to and on return to work
 - Tailored back to work scheme to help the person with cancer with back to work activity such as filling in forms and interviews
 - Rehabilitation/ retraining programme for the patient and their family including exploring new, alternative employment opportunities.
 - An adaption programme – people with cancer may not be able to return to work and will require emotional and financial support.
 - Careers advisors for people with cancer linked in with job centres
- HR policy:
 - Nominated individual within the HR department to whom the person with cancer can go to for fair advice
 - All employers should have a standard sickness and absence policy and a clear process through which grievances can be resolved
- Others:
 - The Trade Union Council (TUC) should ensure that discrimination against people with cancer or constructive dismissal does not occur

- Further legislation is required to break down the barriers people with cancer face when returning to work
- There needs to be a redefinition at the government level of the concept and value of work – for example voluntary work should be valued as it contributes to society and should count in benefits assessments
- Political lobbying to change employment law in relation to the self-employed and small businesses

2. Emotional support

Group discussion

1. Problems with the existing system:

- Ongoing difficulties exist with trying to persuade professionals, especially GPs, to refer to self help and support groups
- The CNS used to provide a co-ordinator role for patients– but now they tend to be more removed from the patient
- Emotional support can not be provided in a one size fits all format which is why gaps exist
- Care is poorly co-ordinated across north Wales
- There is a need for lymphoedema services

2. Possible solutions/improvements:

- Key worker:
 - Patients should have a named key worker for co-ordination of care from diagnosis - someone to champion their needs and act as an advocate when they are most vulnerable. This does not have to be a nurse but it does need to be someone who understands cancer.
 - Easy access to a specialist support nurse before and after surgery.
 - Volunteers could act as buddies, providing emotional support or signposting patients to help
- Learning and development
 - Training for professionals, patients and carers to equip them to cope with emotions e.g. anger management
 - Emotional support should be integral to cancer treatment – at assessment, diagnosis and beyond treatment
 - Medical staff need to give patients space to think through information and make choices
 - Macmillan could raise awareness of the emotional needs of patients with health professionals, possibly through workshops to explore why professionals are apparently reluctant to make referrals
- Environment:
 - Patients need access to a warm and welcoming environment where they feel at ease to open up and share emotions. This should be away from the clinical area where often patients feel they are treated as a condition and number – not a person with a whole range of expectations and fears.
- Access
 - Equity of service delivery : access to right person, right time, right place and in the right environment
 - Special consideration is needed for those aged over 70, people from marginalised communities, those with learning difficulties and those from the BME community
 - Patients need to be assessed based on their emotional needs
 - Patients need access to services during out of hours

- Services should be shaped to include access to long term self-help and support (for ongoing emotional support and to empower the person to live beyond cancer diagnosis and treatment)

3. Practical support

Group discussion

1. Problems with the existing system:

- Hospital professionals may be negative and ill-informed about the practical support that is available.
- GPs only respond to what they see in a consultation and are not aware of problems that may exist at home.
- Some people are reluctant to admit that they are having problems coping. The process of applying for incapacity benefit was cited as being a particularly difficult and undignified experience.
- A distinction must be made between 'information' and 'practical support'. Patients don't just want 'signposting' – they need the practical support to be there when it is needed.
- The needs of carers must be taken into account.
- Hospital based signposting to practical support is often lacking. Particular difficulties may be experienced by patients who have a complex treatment pathway and who may be seeing a number of health care teams in different hospitals.
- GPs are slow to refer to support services.
- There is a shortage of allied health professionals e.g. dieticians, occupational health therapists.
- There is insufficient support for patients following discharge from hospital. Patients continue to live with the consequences of treatment for cancer and continue to need practical support.
- Services are driven by the pressure to meet targets. This seems to have resulted in a breakdown in communication between health and social care teams and across organisational boundaries.
- There are isolated areas of good practice but there must be more opportunity and motivation for health and social care teams to learn from the success of others.

2. Possible solutions/improvements:

- Types of support:
 - Every patient should be given an advocate from point of diagnosis onwards who can signpost them to help and information, can provide help themselves and can contact support on the patient's behalf.
 - There is a broad spectrum of patients/carers, all with very different needs. Individualised assessment is needed.
 - Sources of local support are needed, providing practical support within local communities e.g. provision of child care.
 - Volunteers could act as good neighbours/ handy man, providing various forms of practical support such as transport, child care, home repair etc
 - A local helpline could be set up which people can use if they need help with various jobs or tasks such as changing a light bulb or fixing a tap
 - Separate travel arrangements should be available for those having chemotherapy who are more prone to infections
 - Access to dietician and occupational therapists should be available
 - The volunteer driver service should be expanded and drivers given tax relief for transport costs
 - The assessment criteria for benefits should be improved
 - Child care should be made available at treatment centres eg a patient creche

- Promotion:
 - Support services are often there, but patients are too unwell to search them out – better publicity and information is required including promotion of self help groups. Centres of community (eg village shop) could be used to advertise local or volunteer services
 - A GP champion could help to raise awareness among GPs
 - Early access to personalised information – not just about cancer services but information about social services, travel services etc
 - One helpline could be created which can pass you on to relevant help or support, thereby providing one access route to services
- Health professionals:
 - Improved education is needed amongst health professionals about the support that patients may need and how it can be accessed.
 - GPs should be given a script to help them fill out benefit assessments
 - Each GP surgery should have a GP with an interest in cancer
 - Patient liaison officers should put information into patient discharge bags

4. Information support

Group discussion

1. Problems with the existing system:

- Patients can feel silly asking lots of questions to a medical professional but feel more comfortable talking to a non-professional support worker
- The point was raised that it might not be financially viable to provide these information services
- The language used and comments made by professionals is sometimes inappropriate. The information given by different medical staff is not always consistent
- Sometimes speaking to a person is more beneficial than being given information to take away
- Phone lines are not always manned 24 hours a day and some people are intimidated by them
- There is too much information – it is out dated and duplicated

2. Possible solutions/improvements:

- Key worker:
 - A key worker or patient advocate/buddy is required to give information at the relevant points along the patient's journey, to act as someone who can be contacted (by phone and email) with questions and to help the person with cancer to navigate the system. Macmillan should work out the cost saving to the NHS/society if this service were provided
- Content, quality and format:
 - More information is needed on carer's rights, well being after treatment, nutrition, benefits/ financial issues (particularly for those who are self-employed or own a business), employment, sexual function and fertility, emotional support, travel, complementary medicine and after care
 - More information is required on the side effects of treatment which will require better monitoring
 - Information needs to be relevant, current, regularly updated, targeted not general, and available in a variety of formats
 - An advice hotline is needed for those who are illiterate or have sight problems
 - A kite mark is required so that patients can judge the quality of information
 - A 24 hour help line could provide information whenever a person with cancer requires it

- Services:
 - More information centres are required with people to talk to and localised knowledge. These could be based in libraries, doctor's surgeries or elsewhere within the community. One is required in each local health board
 - There should be a national information service which is delivered regionally
 - Services need to be better coordinated and joined up
 - One helpline could be created which can pass you on to relevant help or support, thereby providing one access route to services
- Promotion:
 - Information needs to be available at medical centres eg leaflets
 - Information support should be advertised for example in the local paper, in hairdressers, supermarkets, coffee shops etc
 - A 'who's who' service list could be created listing all the support resources available
 - The patient should be sent a letter when their first appointment is arranged advising them where to go for information and advising them to bring someone with them so that they can help the patient remember what was said
 - Patients should be given a file of all the needed information including names of key carers, diagnostic and treatment results, cancer specific information, treatment information etc
 - GPs and nurses need to be aware of the information and support available
- Communication:
 - Professionals need more communication training particularly on patient friendly language and empathy
- Other:
 - The reconfiguration of Local Health Boards might provide an opportunity to address these information needs
 - Best practice should be shared (within and outside cancer and across organisations) so that different groups do not duplicate efforts
 - Patient should be given the opportunity to have their appointments recorded so that they can take the recording home with them
 - Volunteers could man out patient clinics and provide information and support to patients and carer
 - Each hospital should have an information manager and someone who is responsible for giving the patient information
 - Support groups are a good source of information – health professionals should direct patients to these

Appendix 2:

Current and future initiatives by Macmillan Cancer Support, and initiatives known to Macmillan by the Welsh Assembly Government (WAG), the Cancer Services Coordinating Group (CSCG) and the Cancer Networks(CNs), to address the support needs of cancer patients and their families.

	Macmillan	WAG, CSCG, CNs
Support	<ul style="list-style-type: none"> • Learnings to be taken from Macmillan Solutions pilot projects (England). Explore feasibility of running a project in Wales, depending on outcome of pilots and available investment. • Continue to invest in Macmillan services, including financial advice and specialist social worker posts. • Macmillan is funding a Rehabilitation lead post for the South West Wales Cancer Network. • Increase local authorities awareness of the need for daily living/emotional support services for people affected by cancer. • Raise profile of Macmillan services, including the soon to be launched new one stop shop helpline, and self help and support groups. • Macmillan to pursue survivorship agenda with WAG and CSCG. 	<ul style="list-style-type: none"> • Development of Cancer Rehabilitation Standards. • CSCG assessment of the on-going needs of cancer survivors and ensuing recommendations. • South West Rehabilitation lead post mapping out current services, identifying gaps and developing recommendations.
Information	<ul style="list-style-type: none"> • Funding all-Wales Patient Information Development project. • Pushing for a Cancer Information Strategy for Wales. • Developing Macmillan's own Information and Support Strategy for Wales. • Provide support to existing Macmillan Information and Support projects at Wrexham and Powys. • Funding additional Cancer Resource and Information Facilitator posts. • Increasing availability of information across Wales e.g. centres, information pod installations, libraries. • Work with a range of partners to develop Macmillan Information and Support resources across Wales. • Increase the availability of Macmillan Cancerbackup resources through the medium of Welsh. • Promote and raise awareness of information and support provision. 	<ul style="list-style-type: none"> • All- Wales Patient Information Development project via the North Wales Cancer Network. • Development of Cancer Information Strategy for Wales. • Developing a web-based resource to provide access to cancer information for patients particularly supporting patients at the time of diagnosis.

Signposting	<ul style="list-style-type: none"> • Ensure Macmillan's patient information strategy includes signposting to support. • Lobby for key-worker/navigator role as part of survivorship/rehabilitation work. • Promote Macmillan direct services (telephone and web support), and indirect services (information centres, etc) through brand advertising and PR activity. 	<ul style="list-style-type: none"> • Draft Cancer Rehabilitation Standards refer to role of key worker.
Coordination of care	<ul style="list-style-type: none"> • Funding Carers Information Adviser post in Cardiff with a view to expanding to other areas during 2009 and 2010. • Macmillan supports self help and support groups who coordinate and signpost to local and national services. • Macmillan services team to hold discussions with new service planners to promote co-ordinated care planning and share best practice Macmillan models. • Continue to lobby for multi agency care plan and assessment at end of treatment 	<ul style="list-style-type: none"> • GPs to view summary details of their patients' management plans. • Key worker/navigator role included in draft Cancer Rehabilitation Standards. • Lobby WAG to put in place arrangements for joint working between health and social service departments and providers.
Data collection	<ul style="list-style-type: none"> • Macmillan funded Thames Cancer Registry work to establish accurate prevalence figures for Wales. 	<ul style="list-style-type: none"> • Collection of the All Wales Cancer dataset
Advocacy	<ul style="list-style-type: none"> • Learnings from Macmillan's Solutions pilot projects (England). • Learnings from Cancer Voices. • Macmillan Welfare Advice services. 	
Self management	<ul style="list-style-type: none"> • Expand availability of Macmillan courses for people affected by cancer in Wales. • Support National Cancer Survivorship Initiative 'Breathlessness self management' project in Velindre • Promote the importance of support groups and self-management to health professionals through Learning and Development programme. 	
Employment support	<ul style="list-style-type: none"> • Macmillan Working Through Cancer resources for employers and employees. 	<ul style="list-style-type: none"> • Support to return to/stay in work included in draft Cancer Rehabilitation Standards.