

Cancer Services Report February 2014





Annabel's Angels

Annabel's Angels is a local community group aiming to raise funds and increase support for patients, carers and families living with Cancer in Derby.

Healthwatch Derby

Healthwatch Derby is an independent consumer champion created to gather and represent the views of the public. Healthwatch Derby plays a role at both a national and local level, making sure the views of the public and people who use services are taken into account.

Please note the two hospital responses are contained within the reports

Introduction

Since the launch of Healthwatch Derby, over 50 comments have been shared with the organisation in regards to cancer services in Derby. 16 positive experiences, 6 negative experiences and 33 comments identifying gaps in services.

‘Recently had cancer care (at The Royal Derby Hospital) and the hospital staff were so kind and caring. The cancer was a rare type but I was fully informed and advised throughout the entire treatment’.

‘My dad recently passed away at The Royal Derby Hospital. His care was not good. I had to do most of his personal care as the nurses didn't do it. He died of cancer’.

‘The cancer unit at The Royal Derby Hospital were great. They really helped me through a very difficult time’.

‘After a six hour wait we were told that the surgery could not go ahead due to a lack of intensive care nurses. We were absolutely devastated and my husband’s health took a serious dip because of this episode. Given the medical imperative for the surgery to take place we were naturally extremely concerned. I wrote a letter of complaint to the Chief Executive Officer of the hospital at that time as I was at a loss to understand why the entire operation was cancelled because they would not employ an intensive care nurse’.

Derby Hospitals NHS Foundation Trust, the largest service provider of cancer services in the city was ranked 10th most improved trust by Macmillan Cancer Support, based on NHS England’s National Cancer Patient Experience Survey 2012 – 2013. The report shows a statistically significant improvement in 8 areas from 2011 – 2012. Derby Hospitals NHS Foundation Trust was in the highest-scoring 20 per cent of trusts in response to 8 of the 67 questions and was in the lowest-scoring 20 per cent for just 1 of them.

As a result of the feedback received Healthwatch Derby decided to undertake an Enter and View into cancer services on 18 December 2013, to further understand people’s experiences, including:

- To explore the experiences of patients at The Royal Derby Hospital;
- To explore the experiences of family, friends and carers of patients at The Royal Derby Hospital;
- To explore the experiences of staff at The Royal Derby Hospital.

Part of the Healthwatch Derby program is to carry out Enter and View visits. Healthwatch Derby authorised representatives carry out visits to health and social care services to see how services are being run and make recommendations where there are areas for improvement.

The Health and Social Care Act allow representatives of Local Healthwatch organisations to enter and view premises and carry out observations for the purpose of carrying on of Local Healthwatch activity including hospitals, residential homes, GP practices, dental surgeries, optometrists and pharmacies. Enter and View visits can happen if people tell us there is a problem with a service, but they can also happen when services have a good reputation – so we can learn about and share examples of what they do well.

Patient, visitor and staff surveys were left at the hospital on the day of the Enter and View visit with freepost envelopes for people to return within a 4 week timescale. The surveys were designed in collaboration with Annabel's Angels to understand people's needs around further support.

From December 2013 to January 2014, 44 respondents took part in the surveys; 16 patient surveys, 9 family, friends and carers surveys and 19 staff surveys.

This report is a snapshot of the over 50 comments shared with Healthwatch Derby by individuals and local groups in the city and the results of the Enter and View surveys.

Disclaimer: This report relates only to the service viewed on the date of the visit, and is representative of the views of the service users, visitors and staff who contributed to the report on that date.



Patient Survey Key Findings

- 14 out of 16 responses said the doctors and nurses talked to them about their illness and why they were in hospital.
- 14 out of 15 responses said they received an explanation about their illness in a way that they understood.
- 13 out of 16 responses said they felt involved in deciding what treatment they received.
- 13 out of 15 responses said they had been offered information and leaflets about their illness.
- 8 out of 16 responses said they had been told where they or their family and friends could get more information about their illness.
- 9 out of 16 responses said a family member (or someone they were close to) had enough opportunity to talk with a doctor with their permission.
- 11 out of 16 responses said there was always someone to help them when they needed it.
- 12 out of 16 responses said they felt comfortable raising a concern or making a complaint if they were unhappy with any aspect of their care.
- 10 out of 14 responses said they were receiving help or support from another service besides the Hospital, including practical support (2 respondents), emotional support (3 respondents), financial support (1 respondent) and other (3 respondents).
- 10 responses said they received help or support from family and or friends and 1 response said they received help or support from a local voluntary organisation.
- 2 responses said they heard about this help or support through information provided by the hospital and 2 responses said they heard about this help or support through another agency.
- 11 responses indicated what extra help or support they felt would make things easier, including housework (5 respondents), shopping (2 respondents), cooking (1 respondent), someone to talk to (3 respondents), joining a support group (2 respondents), accessing benefits (3 respondents), managing a reduced income (4 respondents), transport costs (4 respondents) and other (4 respondents).

Visitor Survey Key Findings

- 8 out of 9 responses said they were made to feel welcome when they come to visit the hospital.
- 7 out of 8 responses said they felt visiting hours were flexible at this hospital.
- 6 out of 8 responses said they felt visitors were supported by staff at this hospital.

- 8 out of 9 responses said they felt that staff were friendly and helpful at this hospital.
- 8 out of 9 responses said they felt that the patients were treated with dignity and respect.
- 5 out of 7 responses said they felt comfortable raising a concern or making a complaint on behalf of the patient if they were unhappy with any aspect of their care.
- 8 out of 9 responses said they were happy with the service of physical and medical care provided at this hospital.
- 6 out of 9 responses said they were happy with the service of emotional care provided at this hospital.
- 1 out of 6 responses said they were receiving help or support from any other service besides the Hospital, including emotional support (1 respondent) and financial support (1 respondent).
- 2 responses said they received help or support from family and or friends and 1 response said they received help or support from another agency.
- 1 response said they heard about this help or support through information provided another agency.
- 3 responses indicated what extra help or support they felt would make things easier including housework (1 respondent), shopping (1 respondent), someone to talk to (3 respondents), joining a support group (1 respondent), accessing benefits (1 respondent), managing a reduced income (1 respondent), transport costs (1 respondent) and other (1 respondent).

Staff Survey Key Findings

- 3 out of 19 responses said they felt there were enough nurses on shift at this hospital to meet the needs of the patients.
- 6 out of 19 responses said they felt there were enough care assistants on shift to meet the needs of the patients.
- 12 out of 19 responses said they felt there were enough housekeeping staff on shift to meet the needs of the patients.
- 5 out of 19 responses said they felt they had enough time to fulfil their duties on shift.
- 14 out of 19 responses said they felt satisfied with their present jobs.
- 5 out of 19 responses said they felt they were asked to do things against their better judgement.
- 12 out of 17 responses said they felt their work was valued at this hospital.
- 11 out of 19 responses said they felt they received adequate support at this hospital, both physically and emotionally.

Enter and View Observations

On the day of the visit, the Enter and View Team visited the Specialist Outpatient Department and in particular The Combined Day Unit.

The Specialist Outpatient Department at The Royal Derby Hospital provides a specialist consultant based service for the assessment, treatment and follow up of cancer patients. Providing a multi-disciplinary team of therapy radiographers, a chemotherapy team and registered nurses as well as access to a dietician, social care worker, pharmacy, counselling and information service. The Combined Day Unit provides care for patients with solid tumours, leukaemia, lymphomas, myelomas and non – malignant haematological conditions through pre – assessment clinics, consultant and nurse led clinics, triage for unwell patients under the care of a consultant, therapies and procedures.

Observations (with Trust Response in Bold)

Specialist Outpatient Department

- ☛ The department was spacious with a calm atmosphere and good information displayed on the walls.

Combined Day Unit

- ☛ The unit was welcoming and decorated nicely.
- ☛ A simple booking system was in place for when patients arrived at the unit.
- ☛ New weighing scales with a frame for people with physical or balance issues were available.
- ☛ The Treatment Room (Room 3) was bright, light with lots of space and curtains for privacy.
- ☛ The Consultation Room (Room 4) was very clean with a nice view from the window.
- ☛ All staff were bare below the elbow in order to improve infection control.
- ☛ All staff were wearing the correct uniforms and were identifiable by their uniform to patients and visitors.
- ☛ There was good information displayed on the walls, relevant to the unit such as tips on nausea and vomiting, informative posters and a staff board displaying photos for patients and visitors.
- ☛ There was a large screw left in one of the toilets. **“Screw removed and domestics asked to remove any items if found when cleaning.”**
- ☛ Christmas decorations on bumper rail needed removing and locating somewhere else to improve infection control. **“Decorations removed 11.12.13.”**
- ☛ The Ward Sister informed the team that ‘The reception area can be too small on busy days, people coming in, people being discharged etc...’ **“Possibility of moving reception/splitting workload - on-going.”**

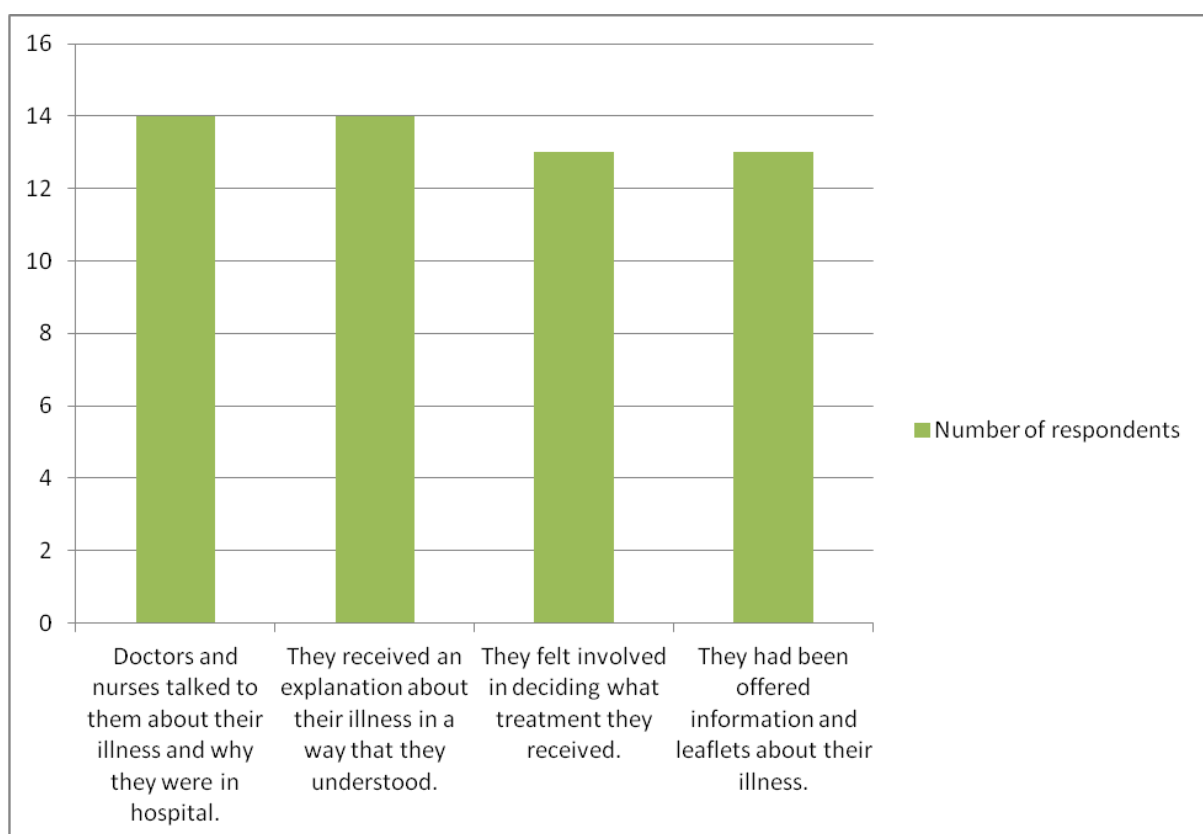
Patient Survey

Respondents

6 responses were from the Combined Day Case Unit, 3 responses were from the Lymphedema Clinic, 3 responses were from Specialist Outpatients, 1 response was from Ward 303, 1 response was from Radiotherapy and 2 responses did not state where they were from.

Patient Experience

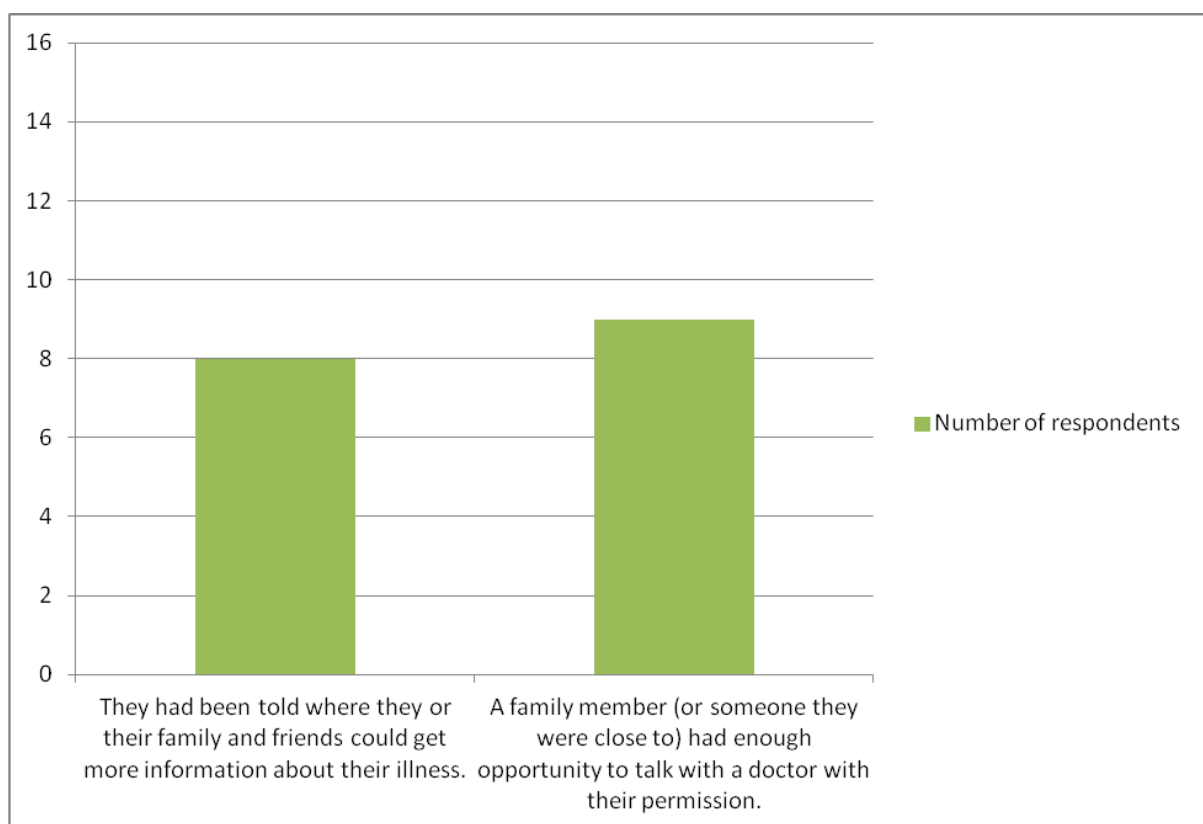
On the whole, the patient surveys indicated that the majority of respondents regarded the experience of being a patient at The Royal Derby Hospital as positive, indicating that they felt informed about their illness, receiving an explanation in a way they understood as well as being offered further information, and involved in decisions around their treatment and care:



Respondents continued to say that they were offered a **‘very clear explanation’**, and that they had **‘been advised of the best course of treatment and happily agreed to it’**.

This echoed what was found in The National Cancer Patient Experience Survey 2012 – 2013, 85% of respondents felt they were told sensitively that they had cancer (84% in 2011 – 2012), 76% of respondents completely understood the explanation of what was wrong (74% in 2011 – 2012), 73% of respondents felt involved in decisions about care and treatment (73% in 2011 -2012) and 75% of people were given written information about the type of cancer they had (67% in 2011 – 2012).

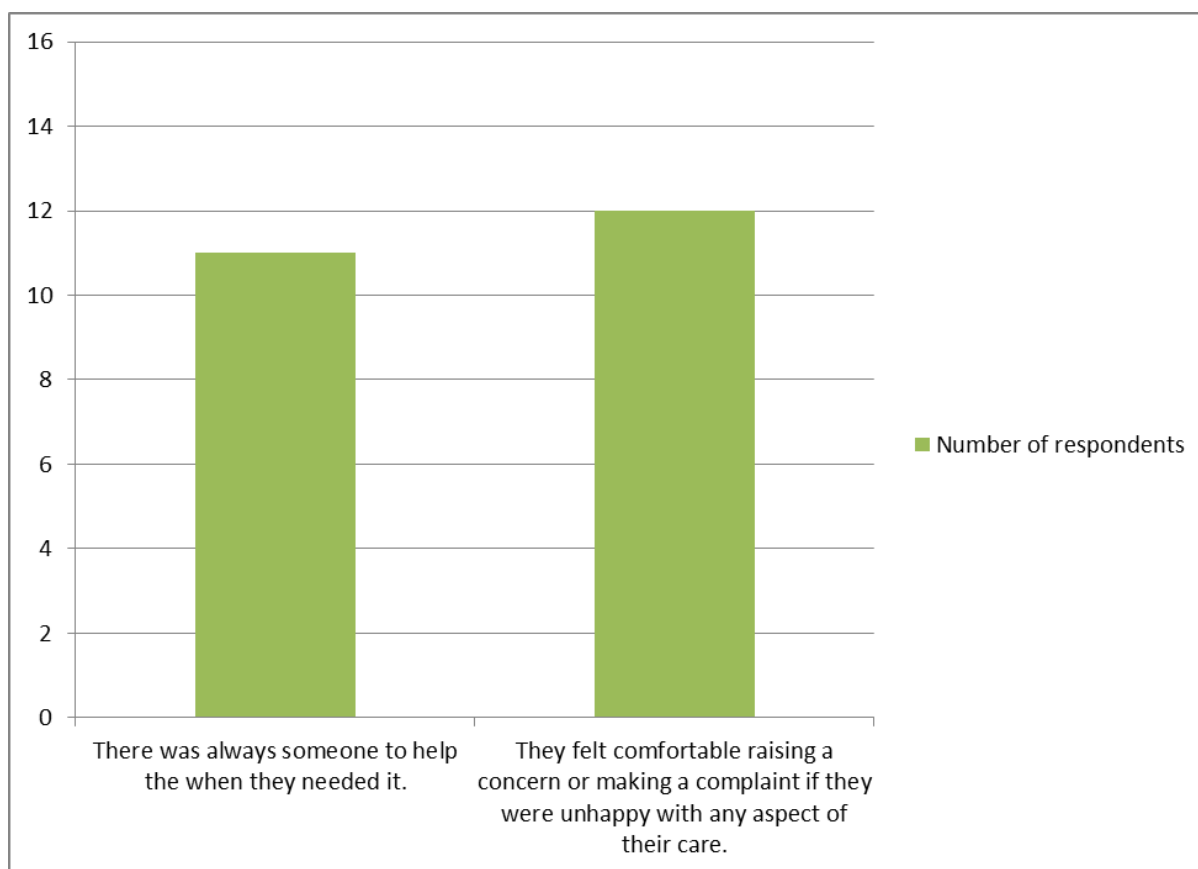
However half of the respondents indicated that provision of information and communication for family or friends was not regarded as highly, with only half of the respondents indicating that they felt their family and friends were told where they could get more information from and just over half of the respondents indicating that they had enough opportunity to talk to a Doctor:



Comments ranged from **‘I have been given a folder with loads of stuff’** to **‘appointments are rushed through due to the number of patients’** and **‘there is never enough time’**.

Again this was echoed in The National Cancer Patient Experience Survey 2012 – 2013, with 68% of respondents indicating that the patient’s family definitely had opportunity to talk to doctor (64% in 2011 – 2012).



The majority of respondents regarded their experience of care as positive stating there was always someone to help and they felt comfortable in raising a concern or making a complaint:



Additionally, The National Cancer Patient Experience Survey 2012 – 2013 states that 84% of respondents felt they were always treated with respect and dignity by staff (84% in 2011 – 2012), asked what name they preferred to be called by, 72%, (71% in 2011 – 2012), always given enough privacy when discussing condition/treatment, 89% (91% in 2011 – 2012) and always given enough privacy when being examined or treated, 96% (95% in 2011 – 2012).

Further Support

In terms of further support 10 respondents said they were receiving help or support from another service besides the Hospital, including:

Type of support	No. of respondents
Emotional (e.g. Counselling, befriending)	
Practical (e.g. Housework, shopping, cooking, childcare)	

Financial (e.g. Accessing benefits, grants)	
Other	   


























‘My GP - The girls and staff at The Dale Medical Centre have been great in arranging for medication to be delivered to me at home. This is not normal practice’.

The majority of support was provided by the family and friends of those affected by cancer, 10 respondents indicated that they received support in this way and 1 respondent also accessed support through a local voluntary organisation.

Respondents cited they had **‘good family help’**, **‘my family and friends have supported me with transport, housework, shopping and most of all love and care’**. Respondents also cited **‘online forums’** and **‘the Macmillan website’** as a source of support.

Respondents indicated that they had heard about this help and support through information provided by the hospital and through other agencies equally.

11 respondents indicated that extra help or support would make things easier, practical support was considered a priority, followed by financial help and advice and peer support:

Support	No. of respondents
Housework	    
Managing a reduced income	   
Transport costs	   
Accessing benefits	  
Someone to talk to	  
Joining a support group	 
Other	   

Comments included it was **‘hard to find out about any benefits you may be entitled to’** and that **‘help with parking costs’** would be appreciated as

‘multiple visits to the hospital cost a small fortune’. Also, **‘more support after treatment has finished’** and **‘someone to talk to’** would be helpful.

Again, this was supported by the findings in The National Cancer Patient Experience Survey where only 58% of respondents said they were given information on getting financial help (52% in 2011 – 2012).

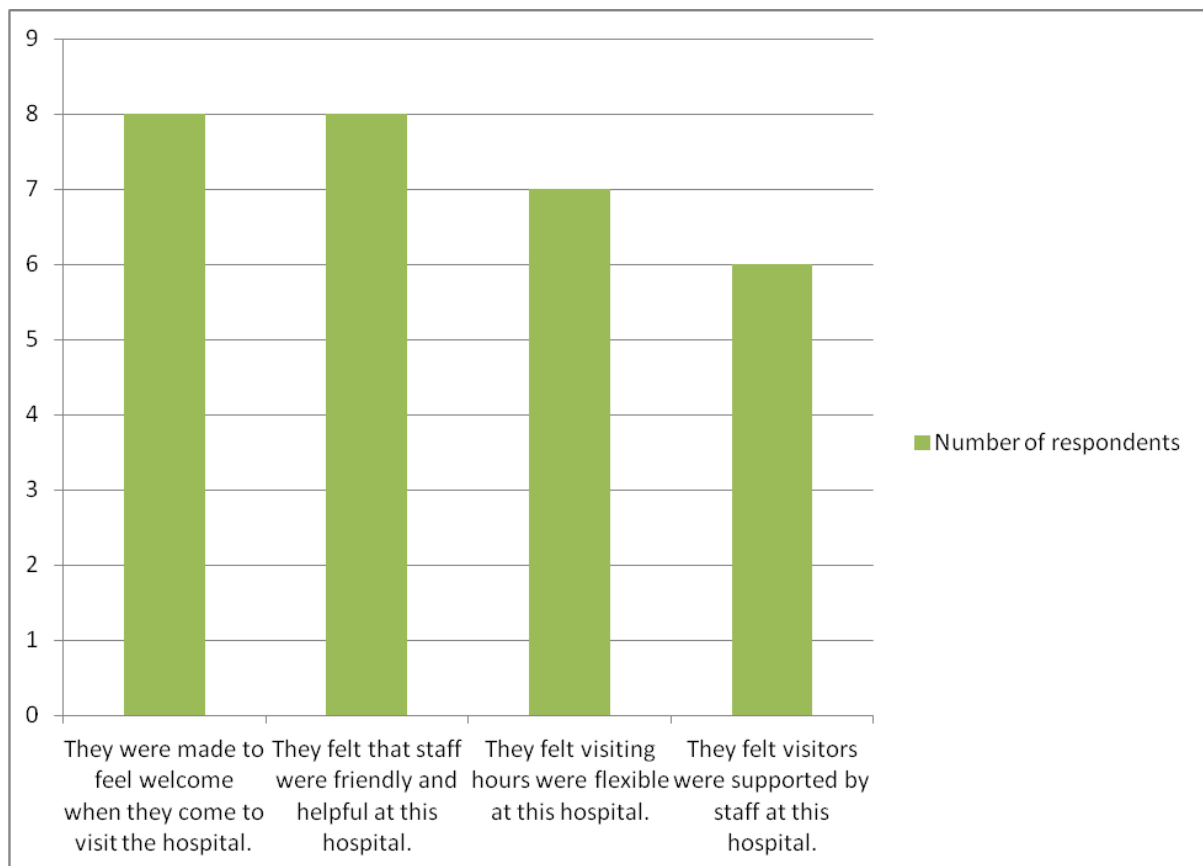
Findings

Visitor Survey

2 responses were from the Lymphedema Clinic, 2 responses were from the Nightingale Macmillan Unit, 1 response was from the Combined Day Case Unit, 1 response was from Specialist Outpatients, 1 response was from Urology Outpatients, 1 response was from Ward 310 and 1 response did not state where it was from.

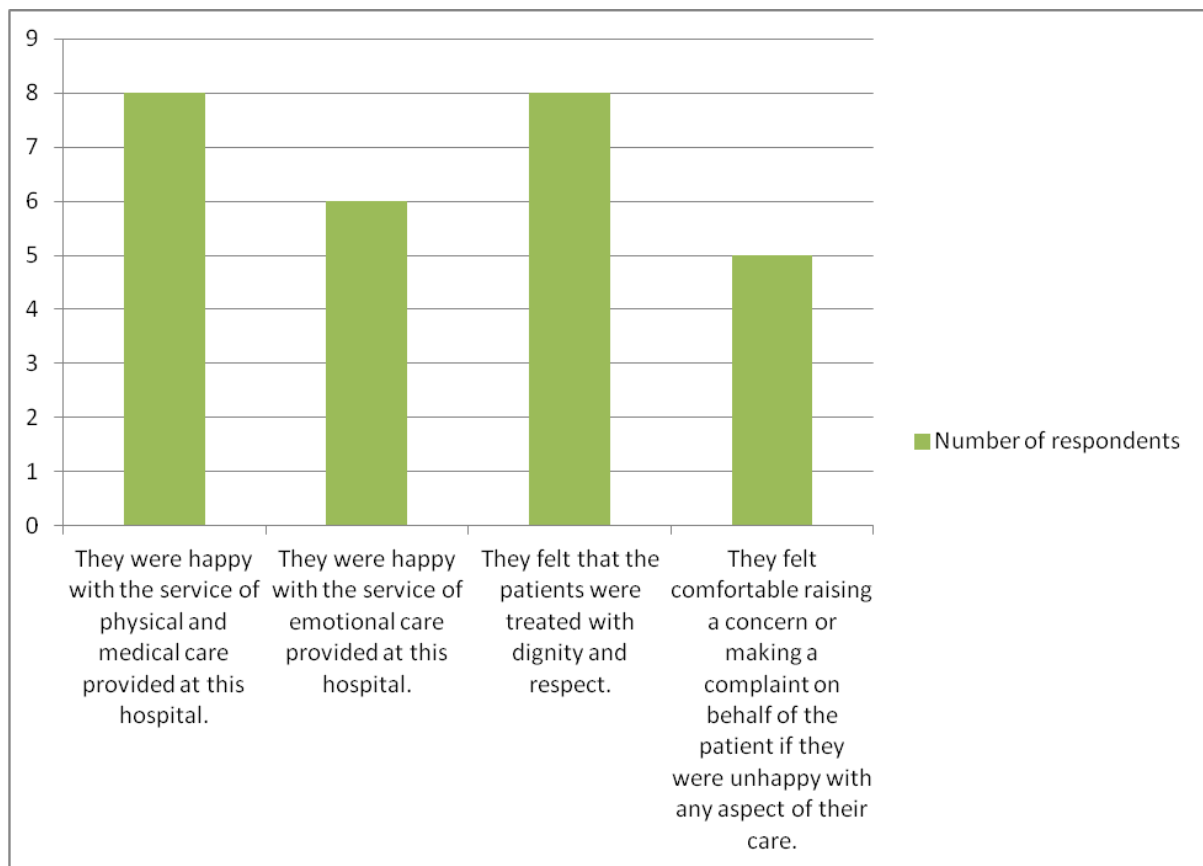
Visitor Experience

On the whole, the majority of respondents regarded their experience of visiting The Royal Derby Hospital as positive, indicating that they felt visiting times were flexible and they were made to feel welcome during their visits by friendly and supportive staff:



Respondents continued to say **‘people at the inquiries desk are very helpful’**, and **‘if you are confused, people ask politely and tell you where to go’**. However, **‘sometimes the differences in the times of visits are confusing’** and **‘staff don’t have time to support family and friends’**.

The majority of respondents also regarded the provision of care as positive and that people were treated with dignity and respect, although a higher number of respondents considered physical and medical care as more positive than the provision of emotional support. Also, just over half of the respondents said they would feel comfortable raising a concern or making a complaint on behalf of the patient if necessary:



Comments included:

‘I accompanied my mother at consultant appointments and she was able to ask questions and she was happy with the response’.

‘The nurses just didn't have the time to spend with me or my wife to provide emotional support’.



‘The patients I have seen have been treated as individuals’.

‘On one occasion my mother was told at 9am she would be leaving that day. She expected to be leaving at 3.30pm so I went to fetch her. It was a Friday and we were there till at least 7.30pm waiting for the pharmacy to provide her medicine. Even the staff encouraged us to complain as they felt frustrated by the delays which were regularly experienced. My Dad wrote a letter of complaint to the Chief Executive but never posted it as he obviously

concerned about whether it would affect my Mum's care. There need to be easier ways of raising concerns'.

Further Support

In terms of further support, only 1 respondent said they were receiving help or support from any other service besides the Hospital, including:











Support	No. of respondents
Emotional (e.g. Counselling, befriending)	
Financial (e.g. Accessing benefits, grants)	

The respondent indicated that this support was received from a local carers group, and that they heard about this help or support through information provided another agency.

Explaining they 'phoned local group' citing 'The Carers Association' as a source of support.

However, 2 respondents indicated that they were supported by family and friends.

3 responses indicated that extra help or support would make things easier were, peer support appeared to be a priority for family and friends of people affected by cancer, followed by practical support and financial help and advice:

Support	No. of respondents
Someone to talk to	  
Joining a support group	
Housework	
Shopping	
Accessing benefits	
Managing a reduced income	
Transport costs	
Other	

In 2011, Ipsos Mori and Macmillan published a report 'More Than A Million – Understanding the UK's carers of people with cancer'.

It outlined that nationally, in the 12 months prior to the research, across the UK, one in seven people (15%) had given some unpaid, informal support to a person with cancer. Half of the carers (49%) say they received no support, compared with almost half who say they got some type of help (45%). Most often they got emotional support from someone they could speak to (20%) or information on cancer and its treatments (13%). The most frequent providers of support to carers were informal: family members (44%) or friends (28%).

Almost half of the carers said they did not get support which would be helpful for them (47%). There was a wide range of support they said they did not receive. Most often it is advice and training on how to give care (10%), followed by information on the general support available (9%) and someone to provide emotional support (9%).

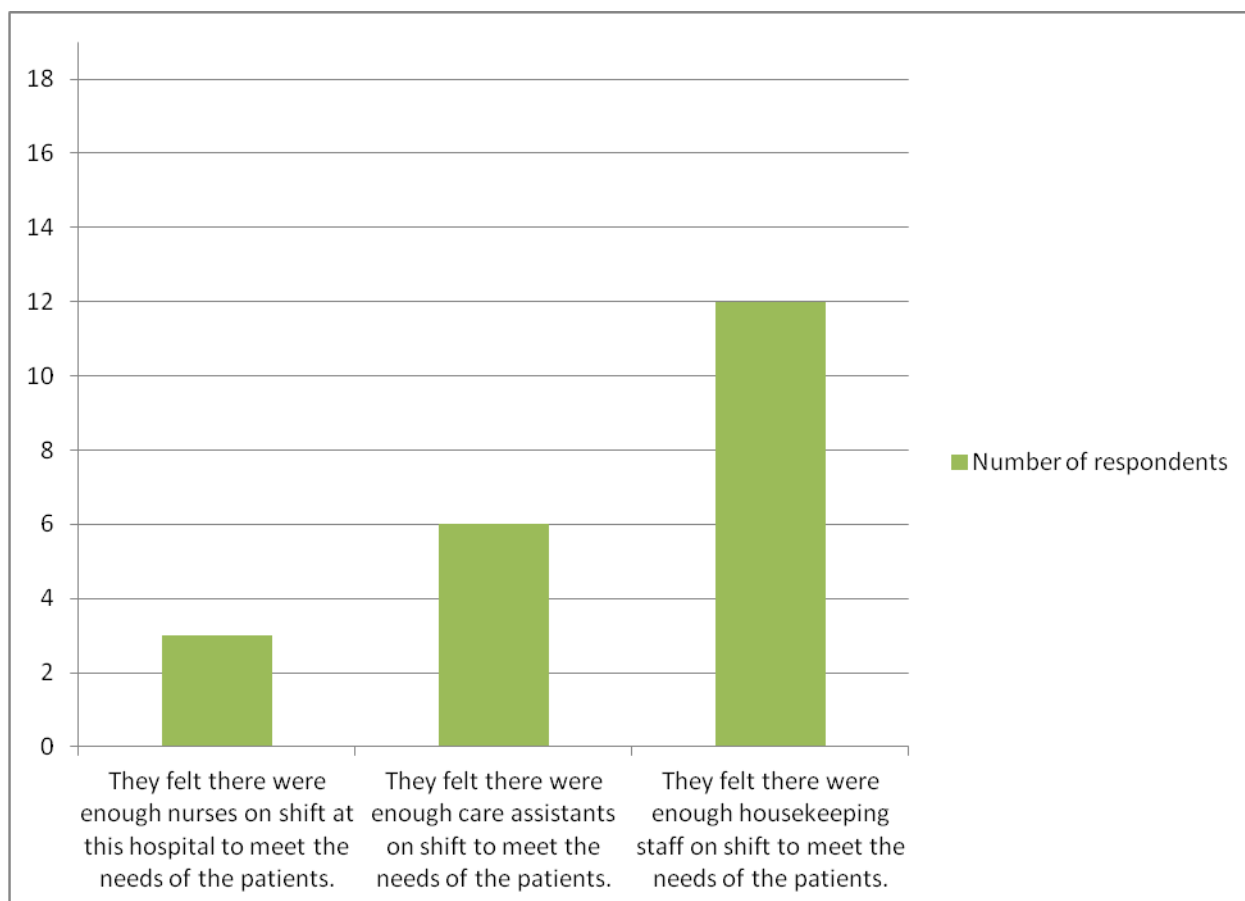
Findings

Staff Survey

7 responses were from the Nightingale Macmillan Unit, 4 responses were from Specialist Outpatients, 2 responses were from the Lymphedema Clinic, 1 response was from Oncology and 5 responses did not state where they were from.

Employee Experience

On the whole, the staff surveys indicate that the majority of respondents regarded the experience of being an employee at The Royal Derby Hospital not as positive as they would like, less than half of the staff who responded felt there were enough staff on shift to meet the needs of the patients, less than half of the respondents felt there were enough care assistants on shift to meet the needs of the patients and just over half of the respondents felt that there were enough housekeeping staff on shift to meet the needs of the patients:



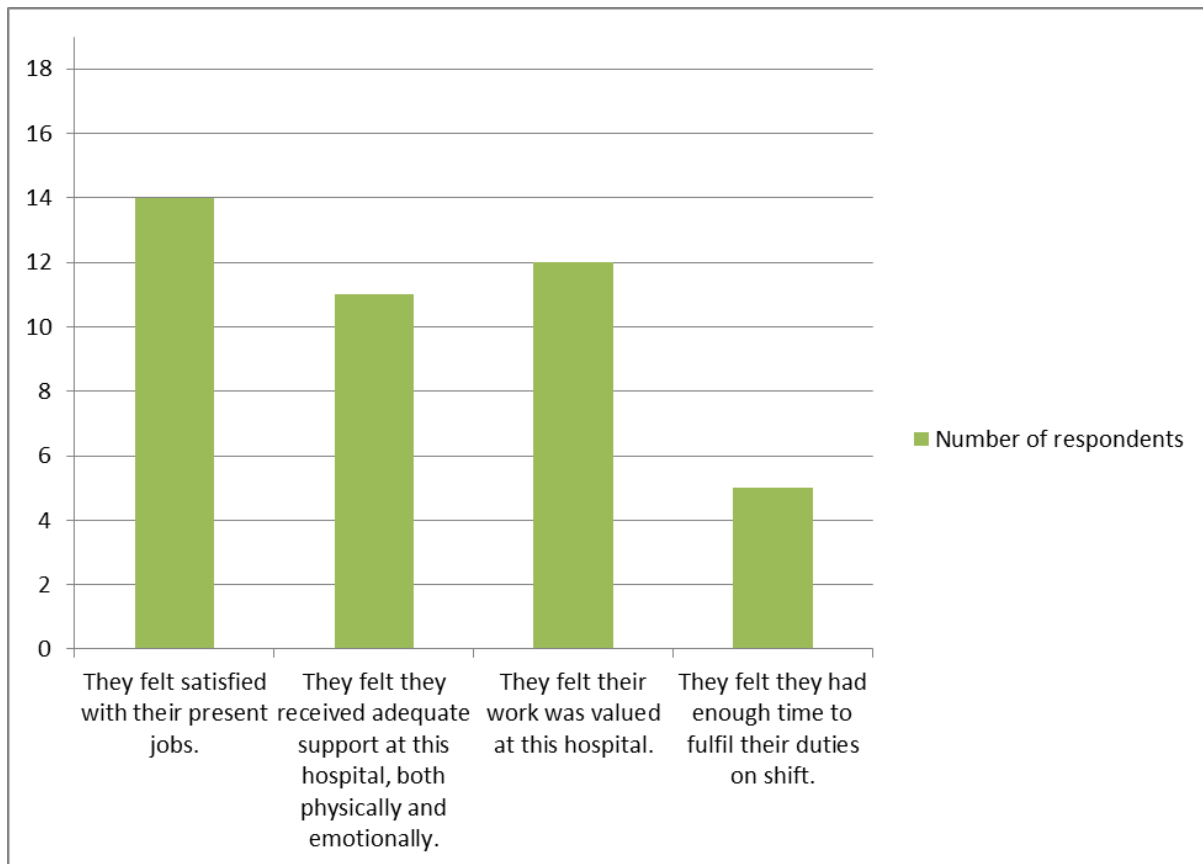
Comments included:

‘Nurses appear continuously stretched on the ward and feel unable to perform their job to a standard they would like’.

‘Staff in general are pressured with time constraints, the ratio doesn't match, it's sad that in end of life care we don't have time to sit with patients and provide tlc’.

‘The housekeeper in our Macmillan Unit maintains the area very well (although I do think every area should have a daily housekeeper)’.

More than three quarters of the respondents felt satisfied with their present jobs and although more than half of the respondents felt they received adequate support, both physically and emotionally and felt their work was valued at the hospital, only 5 respondents felt that they had enough time to fulfil their duties on shift.



Comments included:

‘I love my job and what I do, however, the workload is increasing and it's a push to fulfil my role at times’.

‘I feel like I can get support from my colleagues and line managers’.

‘I feel valued by patients, families and relatives, do not feel valued by the hospital’.

‘I never have time to sit with them and find out who they are’.

5 respondents said they felt they were asked to do things against their better judgement:

Including **‘going to other wards’, ‘sometimes with moving and handling’** and **‘consultants/therapists annual leave okayed by management but don't listen or offer solutions when we escalate that patients will have to wait longer for appointments’.**

Conclusion

In conclusion, the findings identify themes around information, communication and involvement in care; emotional support and future priorities.

Information, communication and involvement in care

Patient information, communication and involvement in care were considered positive at The Royal Derby Hospital. Care is delivered with dignity and respect, although improvements around information and communication for visitors/family and friends/carers were identified, as well as improvements around information regarding raising a concern or making a complaint.

Emotional support

The provision of emotional support for both patients and their visitors/family and friends/carers was identified as an area for improvement at the Royal Derby Hospital. Both patients and visitors who completed the survey felt there was a need for further emotional support and staff who completed the survey acknowledged that there wasn't enough time to provide emotional care.

Future Priorities

Practical support for patients such as help with household chores, shopping and childcare were considered a priority for patients, followed by financial help and advice and peer support.

Peer support for visitors/family and friends/carers was considered a priority, followed by practical support such as household chores, shopping, childcare and financial help and advice.

Recommendations

 Healthwatch Derby recommends that all departments at Derby Hospitals NHS Foundation Trust apply for the Bronze Dignity Award from The Safeguarding Adults Board, to continue to meet the needs of patients with dignity and respect, and to identify areas for improvement, demonstrating their commitment to the 10 Point Dignity Challenge:

1. Have a zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.

4. Enable people to maintain the maximum possible level of independence, choice and control.
 5. Listen and support people to express their needs and wants.
 6. Respect people's right to privacy.
 7. Ensure people feel able to complain without fear of retribution.
 8. Engage with family members and carers as care partners.
 9. Assist people to maintain confidence and positive self-esteem.
 10. Act to alleviate people's loneliness and isolation.
- Healthwatch Derby will aim to facilitate public events and work specifically with local support groups and Derby Hospitals NHS Foundation Trust to develop recommendations around further support for patients affected by cancer and visitors/family and friends/carers of those affected by cancer, and how to implement them.
 - Derby Hospitals NHS Foundation Trust advises patients at the point of diagnosis and during treatment of the existing support available to them in terms of household chores, shopping, childcare, financial help and advice and emotional/peer support. Healthwatch Derby recommends that Derby Hospitals NHS Foundation Trust and voluntary organisations consider setting up a network of volunteers who could help meet these needs and ensure that patients can access support in a variety of ways.
 - Derby Hospitals NHS Foundation Trust advises visitors/family and friends/carers at the point of diagnosis and during treatment of existing support available in terms of information and involvement in care, emotional/peer support, practical support including financial support, shopping and childcare and financial help and advice. Healthwatch Derby recommends that Derby Hospitals NHS Foundation Trust and voluntary organisations consider setting up a network of volunteers who could help meet these needs and ensure that visitors/family and friends/carers can access support in a variety of ways.
 - Derby Hospitals NHS Foundation Trust undertakes a vast amount of work improving services for patients affected by cancer and visitors/family and friends/carers of those affected by cancer. Healthwatch Derby recommends that this work continues to develop and achievements are shared to demonstrate positive patient involvement influencing service provision.
 - The findings indicate that people feel raising concerns or making a complaint may impact on a person's future care. Healthwatch Derby recommends that Derby Hospitals NHS Foundation Trust needs to ensure that feedback and

complaints are welcomed, and are clearly used as a method of sharing best practice and improving services.

- It is important that staff feel supported in their roles both physically and emotionally to deliver a high standard of care that meets the needs of the patients. The majority of staff surveyed did not feel there were enough nurses or care assistants on shift, or that there was enough time to fulfil their duties. Healthwatch Derby recommends that Derby Hospitals NHS Foundation Trust aims to ensure that staff have enough time to fulfil their direct caring responsibilities and pursue their own professional development. It is important that patients and visitors/friends and family/carers perceive staffing levels in each ward and department.

Trust Response

We have taken on board the feedback and recommendations and thank Healthwatch and the people of Derby for providing such valuable feedback. Improving the experience of patients living with cancer is of vital importance to the Trust, and providing information for patients/carers, as well as the freedom to communicate with health professionals, is essential. This will enable patients to be involved in decision making, if they wish, and allow them to fully understand their ongoing treatment. We recognise some patients will need additional support to understand and act upon the information they are given and this will require staff training in good communication skills and regularly updated patient information in plain language, in a variety of formats.

The cancer environment continues to change rapidly as knowledge of how to prevent, diagnose and treat cancer continues to expand. The number of new cases of cancer is set to rise and more people will survive cancer or live for long periods on active treatment. Delivering a world class cancer service will require effective planning. As an organisation we embrace this report and are taking a number of actions from the report forward.

Actions from the Trust

- The Trust is pleased that the majority of patients received a positive experience whilst undergoing treatment for cancer and that they were involved in the treatment plan and decision making.
- The Trust is awaiting the 2013/14 National Cancer Patient Experience Survey and, in conjunction with the Healthwatch report, an action plan and work programme will be devised for the year.
- It is very difficult to achieve the right balance when giving out information at the right time and, as a Trust, we need to revisit the information provided; this will be part of the work programme going forward.
- There should be no delay from being deemed clinically fit before discharge, e.g. waiting for medication.
- The aim is to work with the Trust volunteers to offer practical support. The Lead Cancer Nurse will work with the Patient Experience Team over the coming year, as well as the voluntary sector. Volunteers already play a vital role around the Trust in assisting patients and visitors in finding their

way, signposting them to other services, particularly through our Help to Home service, and companionship on the wards.

- Pathway work is ongoing this year within Cancer Services.
- A working group is to be established around interpreting/sign language services and Macmillan. We already provide a translation and interpreter service centrally, but we know access to this service could be promoted more, as well as the offer of information in other languages.
- We will revisit support groups.
- The Lead Cancer Nurse is working closely with a Macmillan GP to improve communication and ensure a seamless service for all cancer patients.
- Staff do currently have discretion to offer a voucher to a patient if they have been kept waiting beyond 2 hours for an appointment. This is one little thing we can do that would ease anxiety for that patient. We need to make sure staff are fully aware that they can do this. In a project in one of our outpatient units, this has been trialled and has been well received.
- The Lead Cancer Nurse, in conjunction with the Matron, Senior Sister and Clinical Nurse Specialist will revisit job plans and timetable, with the aim of ensuring we can support the patient and carer through the emotional journey, or ensure that we can point them in the right direction.
- Our aim is to discharge all patients as soon as they are clinically ready for discharge, improving the average time of day of discharge by two hours.
- Looking at re-engaging some of the support groups, the Lead Cancer Nurse will work with the Information Centre and Clinical Nurse Specialist to understand the challenges around support groups.
- Work is ongoing with the Trust and Macmillan to acquire additional sessions around benefits; this is also a national problem for cancer patients.
- The Lead Cancer Nurse will work with the Clinical Nurse Specialist around the information that is given to patients and carers, to ensure that it is understood, and to point them in the right direction for help, guidance and support.