Living with & Beyond Cancer



Only 66% felt they were given enough care and help from health and social services.

Very few people (12%) received Holistic Needs Assessments (HNA's) to talk about physical, emotional and/or social needs.

Information and Advice

Q. Would it have been helpful to have had more advice or infor- mation on these areas?	Q. Did you receive any advice or infor- mation on these areas?
I was not offered any	
I have all the information and advice i need	
How to access support groups	
The psychological or emotional aspects of living with and after cancer	
The physical aspects of living with and after cancer	
Information/advice for family/friends/carer	
Returning to or staying in work	
Free prescriptions	
Financial help or benefits	
Physical activity and exercise	
Diet and lifestyle	

Increasing numbers of people are living with, and beyond, cancer, and evidence shows that many of these cancer survivors have unmet needs¹.

We have identified:

- Poor numbers of Holistic Needs Assessments undertaken, which would identify any individual needs and concerns about managing their care from diagnosis.
- A need for more Information and support from the point of diagnosis.
- The psychological and emotional impact of • cancer is not well recognised and more commissioned support is needed during and beyond diagnosis and treatment.
- The communication between professionals • and patients needs to be clearer and organisations do not communicate well together.
- 0 Better follow up support and after care needs to be easily accessible.
 - A persons cancer returning was the biggest concern to patients. This along with not getting support or information and the side effects of treatment was not only a concern, but prevented many from getting the most out of life since a cancer diagnosis.

With only 17% of respondents stating they received all the information and advice they needed, it is clear that more can be done to make sure patients, family and friends can access the information they need.

It seems that individuals of Lincolnshire have received more information regarding free prescriptions but require much more advice and information around the psychological, emotional and physical aspects of living with and beyond cancer.

60% 50% 40% 30% 20% 10% **0%** 10% 20% 30% 40% 50% 60%

1. Armes, J. et al. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. J. Clin. Oncol. 27, 6172-6179 (2009).

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Good

Below are the top things patients told us have allowed them to get the most out of VS life since a cancer diagnosis. (In order)

- Family and friends support. 1.
- 2. A positive attitude.
- 3. Health and social care staff.
- 4. Living life to the fullest / returning to a 'normal' life.
- 5. Support and advice from Macmillan.
- 6. Returning to work.
- 7. Support networks and groups.
- 8. Living healthily.

Top Concerns

1. Cancer returning or spreading.

- 2. Lack of information and support.
- Side effects and health worries 3. associated with cancer including fatigue.

Bad

Below are the top things that have prevented you to get the most out of life since a cancer diagnosis. (In order)

- 1. Lack of psychological aspects / mental health support.
- Lack of information and support. 2.
- 3. Side effects of treatment/operations/ medication.
- Not feeling well enough to do things. 4.
- 5. Fear of cancer returning.
- Unrelated health issues/conditions. 6.
- 7. Financial issues.
- 8. Inconsistent healthcare.

The top concerns about receiving a cancer diagnosis.

- Mental health and emotional support. 4.
- 5. The effect of cancer on family and leaving family behind.
- 6. Quality of treatment in Lincs / inability to access services.
- 7. Quality of Life / Living well / beating cancer.
- 8.

Improvements needed

- 1. Access to Information, advice and support.
- Communication and 2. conversations.
- 3. Greater access to mental health and emotional support.
- 4. Better follow ups and aftercare.

Many people have said they just don't know what's out there to support them, and don't know where to get to the information, advice and support.

People have told us that sometimes the communication between professional and themselves could be clearer and organisations don't communicate well together.

Many have said the psychological and emotional impact of cancer is not well recognised and more could be done to support this.

People have stated they require regular follows and improved aftercare so they feel continually supported



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- Financial / money worries.

What could be improved?

Demographics

243 Respondents as of 28th Feb 2017



26% (62) did not disclose their gender

How long ago.

Nore than 5 yrs

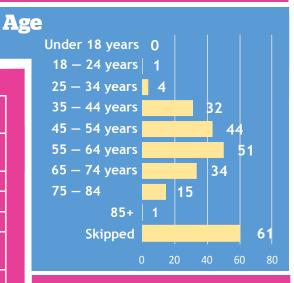
(89,

18 months—5yrs

(89,

Healthwatch Lincolnshire also conducted a quick poll from October 2016 to January 2017, asking cancer patients - if your doctor made an urgent appointment for you to see a specialist in hospital, were you given any information to take home?

Unfortunately 66.2% said they received no information.



How are you affected by cancer?

How are you affected by cancer	No	%
Diagnosed with cancer	59	17%
Undergoing treatment	21	6%
Finished initial treat- ment	33	9%
A carer of someone affected by cancer	34	10%
Under clinical follow up	45	13%
Beyond treatment, coping well	50	14%
Beyond treatment, coping poorly	11	3%
A relative or friend of someone affected by cancer	93	26%
Health Professional	6	2%
Volunteer for Cancer charity	3	1%

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•••	Time since last		
	diagnosis	No	
	Less than 3		
	months	12	5
	3 - 6 months	10	2
	6 - 12 months	32	1
	12 - 18 months	24	1
	18 months - 5		
	years	89	3
	More than 5 years	71	2
	skipped	5	2

1%

3%

7%

9%

%

Primary site of Cancer 🏄 🛃 🍘

Primary area of cancer	No	%	Primary area of cancer	No	%
Breast	83	34%	Lung	13	5%
Colorectal	21	9 %	Head and Neck	11	5%
Prostate	19	8%	Urological	6	3%
Upper Gl	18	7%	Bowel	5	2%
Gynaecological	16	7%	Pancreatic	4	2%
Haematological	15	6%	Other	18	7%

Primary Hospital location

Primary Hospital Location	No	%
Lincoln County Hospital	124	54%
Out of County Hospitals	65	27%
Pilgrim Hospital Boston	35	14%
Grantham and District Hospital	7	3%

4.9% (12) did not disclose.

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Comments received

Below are a selection of comments received from the survey:

"Information and openness regarding treatment and side effects following treatment. Support groups that talk about cancer and give advice not just tea and biscuits."

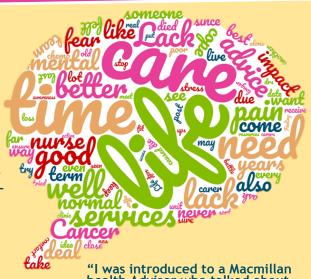
"If someone could have explained more about this terrible disease, the treatment available, and the psychological impact it would have on us and our family."

"I think it would be beneficial to receive more information and practical advice about the long term side effects such as the loss of feeling and chronic fatigue. Many of the side effects are never explained."

"It would also be nice if professionals took a more personal, sympathetic approach and listened to patients choices."

"I think I am lucky to have the good help and support I get from the haematology team at Lincoln Hospital, and cannot think how they could improve their services."

"Outside of the chemo therapy suites I feel the change in a cancer patients emotional and mental wellness after treatment is little understood or appreciated."



"I was introduced to a Macmillan health Advisor who talked about what I could do to improve my health and wellbeing. think how they could improve their services."

"Greater understanding of 'post treatment' crisis and support available for those coming to terms with living with cancer at a stage when it is actually needed, the focus and whirlwind of diagnosis and treatment had passed but then the reality and fear of what if sets in."

"Most definitely the psychological side of things has prevented me getting the most out of life since treatment."

Healthwatch Lincolnshire Hospice Enter & View

In September 2015 Healthwatch undertook visits to Hospices and Hospice in the Hospital settings.

In addition to the patient and carer feedback around the building based services there was a strong emphasis of community based support.

Patients and families told us about challenges in accessing community care packages to enable the patient to be cared for in their place of choice.

The other key theme focussed around the confusing levels and accessibility of community support, which patients and families felt was limited specifically relating to mental health, we heard that dealing with life limiting and changing illness had a direct impact on mental health and that there could be more done within the community to provide psychological assessment and treatment.

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