

Living with & Beyond Cancer

66%

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

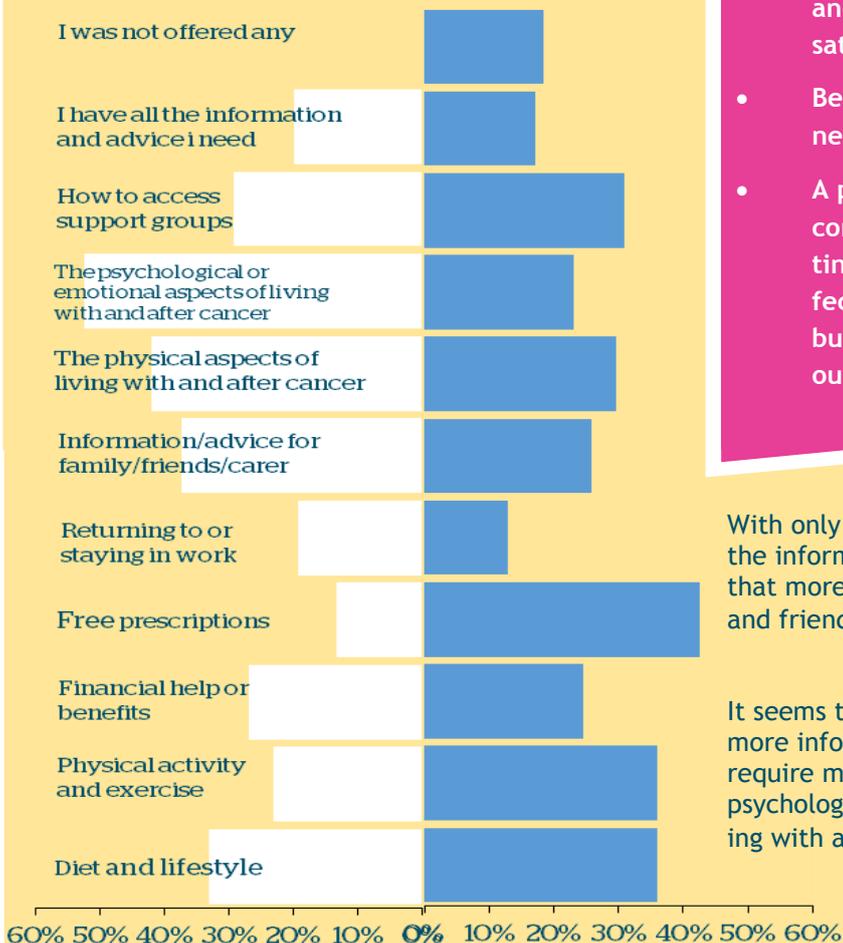
Very few people (12%) received Holistic Needs Assessments (HNA's) to talk about physical, emotional and/or social needs.

12%

Information and Advice

Q. Would it have been helpful to have had more advice or information on these areas?

Q. Did you receive any advice or information on these areas?



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.
- 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.

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 life since a cancer diagnosis. (In order)

1. Family and friends support.
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.

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

vs

Top Concerns

The top concerns about receiving a cancer diagnosis.

1. Cancer returning or spreading.
2. Lack of information and support.
3. Side effects and health worries associated with cancer including fatigue.
4. Mental health and emotional support.
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. Financial / money worries.

Improvements needed

What could be improved?

1. Access to Information, advice and support.
2. Communication and 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

Demographics

243 Respondents as of 28th Feb 2017

18% (44)



56% (137)



26% (62) did not disclose their gender

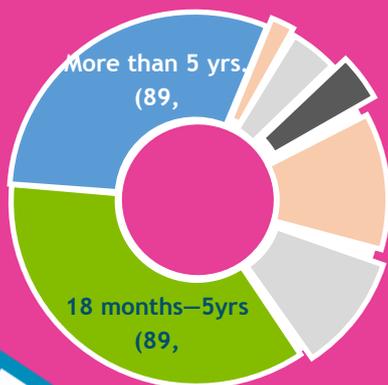
Healthwatch Lincolnshire also conducted a quick poll from October 2016 to January 2017, asking cancer patients – if your doctor made an urgent appointment for you to see a specialist in hospital, were you given any information to take home?

Unfortunately 66.2% said they received no information.

Age



How long ago...



Time since last diagnosis	No	%
Less than 3 months	12	5%
3 - 6 months	10	4%
6 - 12 months	32	13%
12 - 18 months	24	10%
18 months - 5 years	89	37%
More than 5 years	71	29%
skipped	5	2%

How are you affected by cancer?

How are you affected by cancer	No	%
Diagnosed with cancer	59	17%
Undergoing treatment	21	6%
Finished initial treatment	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%

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 GI	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.

