

Experiences of Care Survey

Chemotherapy

*Remove this coversheet before distributing to patient.

Experiences of Care Survey

Are you completing this questionnaire as the patient or on behalf of the patient?

Patient ₁

On behalf of patient ₂

This survey is about the care you received during your cancer treatment.

Taking part in this survey is voluntary. Your responses are confidential. They will be combined with the responses of others in reports.

Completing this survey:

For most questions there is a choice of answers. Pick the response that is true for you and tick the box next to it. Sometimes, more than one box may be ticked. If you make a mistake, scribble out the mistake and put a tick in the correct box.

There is space for you to make any comments about your care.

The instructions before the questions will tell you who should answer the questions. You may be able to skip questions.

The survey may take around 15 minutes to complete.

Words used in the survey

We have used certain words or terms throughout the survey. The following may help to explain what we mean by these terms.

Health professionals: includes doctors, nurses, radiologists, radiotherapists, care coordinators, physiotherapists, dietitians, speech pathologists, social workers and other professions that you may have had contact with during your treatment.

Chemotherapy: is the use of drugs that aim to destroy cancer cells in the body, or to stop them from multiplying and spreading. For this survey, **targeted therapies** are included with chemotherapy. Targeted therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules. Chemotherapy and targeted therapies can be given through a drip that goes into a vein via a needle, as a tablet that you swallow, or as cream that's put on the surface of the skin.

Radiotherapy: is the use of radiation to destroy cancer cells in the body, to slow the growth of cancer, or to reduce the symptoms of cancer. External beam radiotherapy is given using a machine that directs radiation onto the body. Radiotherapy can also be given internally using radioactive implants, which is known as brachytherapy.

Hormonal therapy: aims to control a cancer by changing the hormonal environment in which it is growing. This treatment is used most commonly for breast, ovarian, endometrial and prostate cancer but can be used for some other cancers as well. Treatments can be given by injections into a vein or as a tablet.

Lymphoedema: is a swelling (oedema) due to an accumulation of lymphatic fluid in the body's tissues. It usually affects the arm(s) or leg(s) but can also occur in other parts of the body. Lymphoedema can occur following some cancer treatments.

Diagnosis and treatment overall

1. What cancer were you diagnosed with? If you have been diagnosed with more than one cancer, please indicate the cancer that was diagnosed most recently.

- | | | |
|--|---|--|
| <input type="checkbox"/> ₁ Breast | <input type="checkbox"/> ₈ Uterus | <input type="checkbox"/> ₁₅ Ovarian |
| <input type="checkbox"/> ₂ Leukaemia | <input type="checkbox"/> ₉ Multiple myeloma | <input type="checkbox"/> ₁₆ Lymphoma |
| <input type="checkbox"/> ₃ Prostate | <input type="checkbox"/> ₁₀ Kidney | <input type="checkbox"/> ₁₇ Bladder cancer |
| <input type="checkbox"/> ₄ Colorectal | <input type="checkbox"/> ₁₁ Stomach cancer | <input type="checkbox"/> ₁₈ Pancreatic cancer |
| <input type="checkbox"/> ₅ Lung | <input type="checkbox"/> ₁₂ Mesothelioma | <input type="checkbox"/> ₁₉ Throat/mouth |
| <input type="checkbox"/> ₆ Brain | <input type="checkbox"/> ₁₃ Central nervous system | |
| <input type="checkbox"/> ₇ Sarcoma | <input type="checkbox"/> ₁₄ Melanoma | |
| <input type="checkbox"/> ₂₀ Other cancer (please specify) _____ | | |

2. When was this cancer diagnosed? Please provide the day, month and year. If you cannot remember the day, please provide the month and year. If you cannot remember the month, please provide the year.

D	D	M	M	Y	Y	Y	Y
---	---	---	---	---	---	---	---

3. When you were told you had cancer	Yes, definitely	Yes, I think so	No, I do not think so	No, definitely not	Not sure/ cannot remember
a. Were you given information about your cancer in a format that you were happy with (e.g. written information or being spoken with)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b. Were you given information about the treatment options for your cancer (e.g. written information or being spoken with)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
c. Were you told how you could get more information (e.g. to go to a specific website, how to get booklets, to call the cancer helpline)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
d. Were you given information about who you could contact for support (e.g. another health professional, support group, cancer helpline)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

4 From the list below, could you please indicate the treatments you have had, or are having, for your cancer and the hospital or clinic where you received this treatment.

₁ Surgery \longrightarrow Hospital/Clinic Name_____

₁ Radiotherapy \longrightarrow Hospital/Clinic Name_____

₁ Chemotherapy \longrightarrow Hospital/Clinic Name_____

₁ Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®)

₁ Other (please specify)

5. Were possible short-term side-effects of treatment explained to you before your cancer treatment started (e.g. nausea, pain, fatigue)?

₁ Yes, definitely

₄ No, but I researched this myself

₂ Yes, to some extent

₅ Not sure/cannot remember

₃ No, but I would have liked this information

6. Were possible long-term side-effects of treatment explained to you before your cancer treatment started (e.g. reduced fertility, lymphoedema)?

₁ Yes, definitely

₄ No, but I researched this myself

₂ Yes, to some extent

₅ Not sure/cannot remember

₃ No, but I would have liked this information

7. Throughout your cancer care and treatment, has there been a health professional or a team of health professionals you could contact if you had any questions about your care or if you needed help or advice?

₁ Yes, there was at least one health professional I could contact throughout my treatment

₂ Yes, there was someone I could contact but not all the time

₃ No

₄ Not sure /cannot remember

A Clinical Nurse Specialist is a specialist cancer nurse (e.g. breast care nurse, urology/prostate care nurse) who makes sure you get the right care and gives you help and advice on coping with cancer.

8. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

₁ Yes

₂ No → **PLEASE GO TO THE QUESTION 10**

₃ Not sure/ can't remember → **PLEASE GO TO QUESTION 10**

9. How easy is it for you to contact your Clinical Nurse Specialist?

- ₁ Easy
- ₂ Sometimes easy, sometimes difficult
- ₃ Difficult
- ₄ I have not tried to contact her/him

10. How would you rate how well the doctors and nurses involved in your cancer care worked together?

- | | |
|---|--|
| <input type="checkbox"/> ₁ Excellent | <input type="checkbox"/> ₄ Fair |
| <input type="checkbox"/> ₂ Very good | <input type="checkbox"/> ₅ Poor |
| <input type="checkbox"/> ₃ Good | |

11. How satisfied were you with the overall care you received from all health professionals involved in your treatment?

- | | |
|---|---|
| <input type="checkbox"/> ₁ Very satisfied | <input type="checkbox"/> ₄ Dissatisfied |
| <input type="checkbox"/> ₂ Satisfied | <input type="checkbox"/> ₅ Very dissatisfied |
| <input type="checkbox"/> ₃ Neither satisfied or dissatisfied | |

12. Was there a time when you were so unhappy with your treatment that you wanted to or did complain about it (this includes medical treatment, the way you were treated personally and the way that healthcare professionals communicated with you)?

- | | | |
|--|-------------------|---|
| <input type="checkbox"/> ₁ Yes, there was at least one time | Go to Q12a | <input type="checkbox"/> ₃ No, my care was excellent |
| <input type="checkbox"/> ₂ No, my care was generally fine | | <input type="checkbox"/> ₄ Not sure/cannot remember |

12a. If yes, what was the issue you wanted to complain about?

CHEMOTHERAPY

Please Note: Targeted therapies are included in chemotherapy. If you have had chemotherapy and targeted therapies please think about your chemotherapy when you answer these questions.

13 Did you have chemotherapy treatment for cancer?

₁ Yes

₂ No → **PLEASE GO TO QUESTION 36**

14. When did you start chemotherapy for the first time?

₁ Within the last 3 months

₂ More than 3 months ago, but less than 6 months ago

₃ More than 6 months ago, but less than 12 months ago

₄ More than 12 months ago, but less than 2 years ago

₅ More than 2 years ago

₆ Not sure/cannot remember

15. Where did you have your chemotherapy treatment? (Please indicate name of hospital/treatment centre and the town/suburb or postcode of where the hospital/treatment centre is located)

Name of hospital _____ **AND**

Town/suburb/postcode _____

16. Who made the decision to have your chemotherapy at this hospital/treatment centre? (please choose one response)

₁ I made the decision with little or no input from my doctor

₂ I made the decision after considering my doctor's opinion

₃ My doctor and I made the decision together

₄ My doctor made the decision after considering my opinion

₅ My doctor made the decision with little or no input from me

₆ Other (*please specify*) _____

₇ Not sure/cannot remember

17. Did you have any bills associated with your chemotherapy that you had to pay (e.g. bills from the doctor, the hospital, for tests or medications you may have had etc.)?

₁ No, I did not have any bills associated with my chemotherapy **GO TO Q.19**

₂ Yes, and my health insurance covered these costs completely

₃ Yes, and my health insurance covered only some of these costs

₄ Yes, I had bills to pay

17a. What sort of bills did you have? (please provide a brief description of the type of bills you had)

18. Before you started your chemotherapy, were you told or given information about the out-of pocket costs you might have to pay?

- ₁ Yes, I was fully informed of the costs I would have to pay
- ₂ Yes, I was informed, but not of the full amount
- ₃ No, I was not informed of the costs involved
- ₄ Not sure/cannot remember

19. Did you have to stay away from home while receiving chemotherapy (e.g. at the home of a friend or relative, or in a hotel or hostel)?

- ₁ Yes →
- ₂ No

19b. Who arranged this accommodation?

- ₁ I did/my family or friends did
- ₂ Staff at the hospital
- ₃ Staff associated with my doctor
- ₄ Not sure/cannot remember
- ₅ Other _____

20. Sometimes other treatments or tests need to be completed before a person is ready to start chemotherapy treatment. Once you were ready to begin chemotherapy, how long did you wait until you had your first chemotherapy treatment?

- ₁ Less than 2 weeks
- ₂ More than 2, but within 4 weeks
- ₃ More than a month →
- ₄ Not sure/cannot remember
- ₅ Other: _____

20b. If more than two weeks was this due to:

- ₁ Personal decision to wait
- ₂ Chemotherapy waiting times. I was kept updated
- ₃ Chemotherapy waiting times. I was **not** updated
- ₄ Other: _____

21. Before starting chemotherapy for the <u>first</u> time were you given information about:	Yes, I was given this information	Yes, but I would have liked more	I was not given this information	Not sure/cannot remember
a. How to prepare for chemotherapy (e.g. changes to other medications)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. How to manage any anxiety or stress you might feel before your chemotherapy treatments (e.g. relaxation exercises etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. How you would feel at the end of the chemotherapy treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

d. What side-effects you might experience from chemotherapy?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. How to manage any side-effects of chemotherapy at home?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
f. The possibility of going to the Emergency Department if you had a bad response to your chemotherapy?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

22. Did a health professional check that you understood the information provided to you?

- ₁ Yes ₂ No ₃ Not sure /cannot remember

23. Did staff take into account how far you had to travel or other commitments when arranging your appointment times (e.g. work, caring for family members)?

- ₁ Yes, definitely ₄ Travel/other commitments were not a problem
₂ Yes, as much as they could ₅ Not sure/cannot remember
₃ No, not at all

24. On average, how long did you wait at your chemotherapy appointments before you had your treatment?

- ₁ I generally had treatment within 15 minutes of my appointment time
₂ I generally had treatment within 15-30 minutes of my appointment time
₃ I generally had treatment within 30-60 minutes of my appointment time
₄ I generally had treatment within 1-2 hours of my appointment time
₅ I generally waited longer than 2 hours for my appointment
₆ My chemotherapy was given in a tablet form. This wasn't a problem for me
₇ Not sure/cannot remember

25. While you were having chemotherapy, did health professionals check if you had any side-effects or symptoms (e.g. pain, vomiting, constipation or diarrhoea, hair loss, tiredness, tingling or loss of feeling in the fingers and toes etc.)?

- ₁ Yes ₃ No
₂ Yes, but not as often as I would have liked ₄ Not sure/cannot remember

26. Do you think the health professionals involved in your chemotherapy did everything they could to help manage any side-effects you experienced?

- ₁ Yes, definitely ₄ I did not have any side-effects
₂ Yes, to some extent ₅ Not sure/cannot remember
₃ No

27. Did the health professionals involved in your chemotherapy treat you with respect and dignity?
- ₁ Yes, always ₃ No
₂ Yes, sometimes ₄ Not sure/cannot remember
28. Did the health professionals involved in your care check if you needed any help or assistance with things like your diet or eating, etc.?
- ₁ Yes ₂ No ₃ Not sure /cannot remember
29. Did the health professionals involved in your care check if you needed any help or assistance with managing your emotional state (e.g. feeling stressed or anxious, feeling sad or down etc.)?
- ₁ Yes ₂ No ₃ Not sure /cannot remember
30. Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?
- ₁ Yes ₂ No ₃ Not sure /cannot remember
31. Were you given a telephone number to contact if you had concerns, questions or became unwell because of your treatment?
- ₁ Yes ₂ No ₃ Not sure /cannot remember
32. Were you given a card or some other document that explained your chemotherapy treatment to show if you needed to go to the Emergency Department?
- ₁ Yes ₂ No ₃ Not sure /cannot remember
33. Did the health professionals involved in your chemotherapy ask if your family or friends needed any information or support?
- ₁ Yes, regularly ₄ No family or friends were involved
₂ Yes, occasionally ₅ Not sure/cannot remember
₃ No, never
34. How satisfied were you with the availability of car parking at the treatment centre where you had chemotherapy?
- ₁ Very satisfied ₄ Dissatisfied
₂ Satisfied ₅ Very dissatisfied
₃ Neither satisfied or dissatisfied ₆ Not applicable
35. Overall, how satisfied were you with the treatment you received from all health professionals involved in your chemotherapy?
- ₁ Very satisfied ₄ Dissatisfied
₂ Satisfied ₅ Very dissatisfied
₃ Neither satisfied or dissatisfied

If you would like to make any other comments about your experiences chemotherapy, please use the space below. We would like to know about them.

EMERGENCY DEPARTMENT EXPERIENCES

Sometimes people become very unwell during their cancer treatment and need to go to an Emergency Department.

36. Have you felt so ill from your cancer or cancer treatment that you have had to go to an Emergency Department?

- ₁ Yes, only once
₂ Yes, more than once
₃ Yes, but it was before my cancer was properly diagnosed
₄ No, never → PLEASE GO TO QUESTION 42

37. Which hospital Emergency Department did you last go to? (Please indicate name of the hospital and the town/suburb or postcode of where this hospital is located)

Name of hospital _____ AND
Town/suburb/postcode _____

38. The last time you were at the Emergency Department, about how long did you have to wait before you saw the doctor?

- ₁ Less than 10 minutes
₂ More than 10 minutes, but less than 30 minutes
₃ More than 30 minutes, but less than 1 hour
₄ Between 1-2 hours
₅ Between 2-4 hours
₆ More than 4 hours
₇ Not sure/cannot remember

39. Do you think that your condition was well managed while you were waiting to see an Emergency Department doctor?

- ₁ Yes, my condition was managed well
₂ No, my condition was **not** managed well
₃ Not sure/cannot remember

40. Do you think that the health professionals in the Emergency Department had the knowledge and skills needed to look after you?

- ₁ Yes, all or most of them did
₂ Only a few of them did
₃ No
₄ Not sure/cannot remember

41. Were you admitted into hospital as a result of your consultation with doctors at the Emergency Department?

- ₁ Yes ₂ No ₃ Not sure /cannot remember

If you would like to make any other comments about your experiences with the Emergency Department, please use the space below. We would like to know about them.

YOUR BACKGROUND

42. What is your gender?

- ₁ Male
₂ Female

43. How old were you at your last birthday? _____ years

44. What is the name or postcode of the town/suburb where you currently live?

Town/Suburb _____ **OR**
Postcode _____

45. Where were you living when you received your treatments for cancer?

- ₁ Same address as above
₂ Different address: Town/Suburb _____ **OR**
Postcode _____

46. What language do you mainly speak at home?

- ₁ English
₂ Italian
₃ Greek
₄ Cantonese
₅ Arabic (including Lebanese)
₆ Vietnamese
₇ Mandarin
₈ Other (*please specify*)
-

47. Are you of Aboriginal or Torres Strait Islander origin?

- ₁ Yes, Aboriginal
₂ Yes, Torres Strait Islander
₃ Yes, both Aboriginal and Torres Strait Islander
₄ No

48. In general, how would you rate your health?

- ₁ Excellent
₂ Very good
₃ Good
₄ Fair
₅ Poor

Thank you very much for completing the questionnaire.

If you have any other comments on your care or suggestions for improvements please use the following pages to let us know what you think.

Thank you.

If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them.
