

# Cancer Survivors' Unmet Needs (CaSUN)

Survivors of cancer sometimes report ongoing issues and the need for various services many years after the completion of treatment. The following statements cover a range of different issues which survivors of cancer may face. The issues include:

- information and medical care issues
- quality of life
- emotional and relationship issues
- and the impact of cancer on your life perspective.

We want to learn about your need for services RIGHT NOW. Whilst we recognise that people may have had many needs at diagnosis and during treatment, this study is focusing on your needs AFTER your primary treatment finished. Your responses will enable us to make recommendations about what sort of supports and services should be available to survivors of cancer and their families in the future. We also want to know about any positive changes to your life that you may have experienced as a result of your cancer. Please tick the answer that best describes your experience. There are no right or wrong answers.

**EXAMPLE    EXAMPLE    EXAMPLE    EXAMPLE    EXAMPLE    EXAMPLE    EXAMPLE**

	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
<b>In the last month...</b>					
<b>1. I need up to date information...</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

\* This person has needed information following the completion of their cancer treatments and this need is moderately strong.

	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
<b>In the last month...</b>					
<b>2. My family and/or partner needs information relevant to them...</b>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* This person's partner/family has a need for information but this need is currently being met.

**(A) Information Needs & Medical Care Issues: The first few questions ask about your current need for information and your experience of medical care.**

In the last month...	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
1. I need up to date information...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My family and/or partner needs information relevant to them...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I need information provided in a way that I can understand...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I need the very best medical care...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I need local health care services that are available when I require them...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I need to feel like I am managing my health together with the medical team...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I need to know that all my doctors talk to each other to coordinate my care...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I need any complaints regarding my care to be properly addressed...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I need access to complementary and/or alternative therapy services...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**(B) Quality of Life: The next few questions ask about the impact that cancer has had on various areas of your life, including your health and daily activities.**

In the last month...	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
10. I need help to reduce stress in my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I need help to manage ongoing side effects and/or complications of treatment...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I need help to adjust to changes in my quality of life as a result of my cancer...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I need help with having a family due to fertility problems...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I need assistance with getting and/or maintaining employment...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I need help to find out about financial support and/or government benefits to which I am entitled...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Due to my cancer, I need help getting life and/or travel insurance...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Due to my cancer, I need help accessing legal services...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I need more accessible hospital parking...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**(C) Emotional & Relationship Issues: These next few questions ask about your emotional responses to surviving cancer, and the impact that cancer has had on your personal relationships.**

In the last month...	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
19. I need help to manage my concerns about the cancer coming back...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I need emotional support to be provided for me...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I need help to know how to support my partner and/or family...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I need help to deal with the impact that cancer has had on my relationship with my partner...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I need help with developing new relationships after my cancer...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I need to talk to others who have experienced cancer...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I need help to handle the topic of cancer in social and/or work situations...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I need help to adjust to changes to the way I feel about my body...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I need help to address problems with my/our sex life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I need an ongoing case manager to whom I can go to find out about services whenever they are needed...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**(D) Life Perspective: Sometimes survivors of cancer report that their cancer experience has changed the way they view their life, their future. These next few questions ask about these issues.**

In the last month...	NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
	No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
29. I need help to move on with my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I need help to cope with changes to my belief that nothing bad will ever happen in my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I need help to cope with others not acknowledging the impact that cancer has had on my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I need help to deal with my own and/or others expectations of me as a "cancer survivor"...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I need help to try to make decisions about my life in the context of uncertainty...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I need help to explore my spiritual beliefs...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I need help to make my life count...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**36. Please list any other needs that you have experienced in the last month:**

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**(E) Positive Changes:** The final few questions ask you about positive changes that you may have experienced as a result of your cancer.

**NB:** Please note that the response options are different to previous questions.

<b>In the last month...</b>	<b>Yes, but I have always been like this</b>	<b>Yes, this has been a positive outcome</b>	<b>No, and I would like help to achieve this</b>	<b>No, and this is not important to me</b>
37. I have benefited from contact with other cancer survivors and/or their families...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I focus more on things that are important...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I realise how precious life is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I have made lots of positive changes in my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I have grown as a person...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. I appreciate my relationships with others more....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

**THANK YOU FOR YOUR TIME**

**During the course of completing this questionnaire, you may have realised that you would like some additional support.**

**Please contact your local doctor, your treatment team, or your local Cancer Council for information on available services.**