

Cancer Survivors' Partners Unmet Needs (CaSPUN)

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

- information and medical care issues;
- quality of life
- emotional issues 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 you may have had many needs at the time of the diagnosis and during treatment, this study is focusing on your needs AFTER your partners' primary treatment finished. Please always ensure that you answer the questions in regard to YOUR OWN EXPERIENCE AS A PARTNER of a survivor of cancer, not in regard to what your partner may have experienced or may be experiencing. Your responses will enable us to make recommendations about what sorts 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 partner's 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
In the last month...					
1. I need up to date information...	<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 partners' 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
In the last month...					
2. I need information relevant to my needs as a partner...	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* This person's partner 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 your partner's 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. I need information relevant to my needs as a partner...	<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 local health care services that are available when my partner requires them...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I need to feel like I am managing my partner's health together with the medical team...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I need to know that all my partners' doctors talk to each other to coordinate my partner's care...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I need any complaints regarding my partner's care to be properly addressed...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(B) Quality of life: The next questions ask about the impact that your partners' cancer has had on various areas of their life and your own life.

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
8. I need help to reduce stress in my partner's life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I need help to manage ongoing side effects and/or complications that my partner experiences as a result of their treatment...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I need help with my own health problems...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I need my partner to have 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"/>
12. I need more accessible hospital parking...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I need help to deal with changes to my partner's working life and/or usual activities...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I need help to deal with the impact that my partner's cancer has had on my working life and/or usual activities...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I/we need help to find out about financial support and/or government benefits to which we are entitled...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Due to my partner's cancer, we 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 partner's cancer, I/we need help accessing legal services...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(C) Emotional & Relationship Issues: These next questions ask about the impact that your partner's cancer has had on you and 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
18. 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"/>
19. I need emotional support to be provided for me...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I need help communicating with my partner and/or family...	<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 emotional support to be provided for my loved ones...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I need to talk to others who have had a partner experience cancer...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. 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"/>
25. I need help to manage additional responsibilities as a result of my partner's illness...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I need help dealing with changes that cancer has caused in my partner...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. 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"/>
28. I need help adjusting to changes to my partner's body...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I need help to address problems with our sex life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. We 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"/>

(D) Life Perspective: Sometimes partners of survivors of cancer report that the cancer experience has changed the way they view their life, their spirituality, and 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
31. My partner needs help to move on with their life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I need help to cope with others not acknowledging the impact that having had a partner experience cancer has had on my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I need help to cope with trying 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 or your partner have experienced in the last month:

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

Please note the response options are different to those in previous questions

In the last month...	Yes, but I have always been like this	Yes, this has been a positive outcome	No, and I would like help to achieve this	No, and this is not important to me
36. 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"/>
37. I focus more on things that are important...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I realise how precious life is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I have made lots of positive changes in my life...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I have grown as a person...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I appreciate my relationships with others more...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

42. Comments:

THANK YOU FOR YOUR TIME

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

If so, please contact your local doctor, your treatment team, or your local Cancer Council for information on available services.