

Cancer in the Workplace Project:

Report on consultations with Managers and Employees

on behalf of

The Cancer Council Western Australia

by

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Report on Consultations with Managers and Employees

1 Background

The Cancer Council Western Australia (TCCWA) hosted a State Cancer Conference in 2003, during which a consumer planning session identified that some employers are poorly prepared to support employees who become diagnosed with cancer. This prompted TCCWA to instigate the *Cancer in the Workplace Project* (the Project) to investigate this issue with the goal of developing guidelines to facilitate workplace challenges that arise when an employee is diagnosed with cancer.

2 Procedure

Three groups were identified for consultation on the Project: people diagnosed with and/or undergoing treatment for cancer while employees; the managers and supervisors of such employees; and employees caring for loved ones with cancer. Separate paper-based questionnaires for each group were developed. Included at the end of each questionnaire was an item that asked respondents if they would be interested in participating in further detailed research, and if so to leave details of how they could be contacted. Questionnaires were distributed *en masse* with pre-paid self-addressed return envelopes between in 2004 and 2005 [see questionnaires in appendices]. Over 1,000 surveys were distributed in this way. The Centre for Behavioural Research in Cancer Control (CBRCC) was then appointed to conduct the follow-up qualitative research with the successfully recruited volunteers in July 2005.

3 Results

3.1 Participants

The response rates were extremely low for all surveys (~10%) with questionnaires being returned by 61 employees, 20 employers and 19 carers. One employee and one carer were not in paid employment at the time of their cancer experiences so their responses were not included in further analyses. The number of females (n=52) who responded to the employee survey far exceeded the number of males (n=8). As the incidence rates of cancer are actually slightly higher in Western Australian males (1 in 3) than females (1 in 4), this suggests a clear level of response bias to the employee survey.¹ The response to the carer survey was more evenly balanced between females (n=11) and males (n=8). The majority of respondents for both surveys were aged between 51–69 years (67.2% of employees and 63.2% of carers). Demographic information about employer respondents was not included in the questionnaire for employers, but information about the organisations they represented suggested responses from a roughly equal mix of government (55%) and non-government (45%) institutions with an average of 265 employees each (range 13–1,000).

TCCWA was able to recruit six employees and three managers to participate in follow-up interviews, but was unsuccessful in recruiting any carers. The sex bias for the employee survey was reflected in the sex mix of the follow-on consultations with five women and one man being successfully recruited. Two of the employers in the follow-on interviews were males and one female.

The low response rates to the surveys, the modest extent of follow-on consultations, and heavy sex bias for employees, must all be acknowledged as limitations of the present consultation strategy. As such the results must be interpreted with caution and no assumptions should be made about the representativeness of the findings. For example, 40% of surveyed employers (n=20) believed that cancer had affected the ability of their employees to perform the essential duties of their jobs (see page 9). Given the sample size, 95% confidence intervals for this figure are +/-21%. So even before taking

¹ Threlfall, T., & Thompson, J. (2004). *Cancer incidence and mortality in Western Australia, 2002*. Perth: Department of Health, Western Australia.

into account response bias, we can only assume the true figure is somewhere between 19–61%. As such, the data gleaned from the surveys and follow-on consultations presented hereafter should be viewed as exploratory rather than definitive.

3.2 Informing Work of a Cancer Diagnosis

3.2.1 Informing Management

The survey of employees suggested a majority (n=46; 76.7%) informed their employers immediately upon learning of their cancer diagnoses, with most of the remainder (n=10; 16.7%) informing their employers within one week. Consistent with this trend, all focus group participants suggested that they informed their employers within a matter of days, and the interviewed employers seemed to view this as the norm also. Similarly, a majority of carers (n=15; 83.3%) stated that they informed their employers straightaway or within one week. Only one carer stated that he did not inform his employer about his loved one being diagnosed with cancer, but no explanation for his reason for doing so was offered.

One of the managers emphasised the importance of respecting the wishes for privacy of employees if they did not wish for anyone else to know, but suggested that it would be very difficult for an employee to conceal their illness for very long, especially from the “caring and observant” colleagues in her organisation. It was also reported by the employers in the interviews that none of their organisations actually had policies in place to compel employees to report a diagnosis of cancer or similar illness.

None of the employees in the focus-group but one-third of surveyed employees (n=20; 33.3%) reported being ‘anxious or nervous’ about informing their managers of their cancer diagnoses. Few carers (n=3; 16.7%) reported similar angst. Open-ended explanations given for such hesitancy by employees appeared largely related to:

- uncertainty about supervisors’ reactions (n=7);

“My employer was really angry with me as I would need time off”

“Simply because I was unsure how they would respond to the news”

- recent commencement of work with their employer (n=6);

“I had just started the job 2 months previously and was living in Australia with no family”

- job security (n=4);

“I thought that I may be discriminated against regarding shifts, hours and workplace area”

“I was unsure of what their response would be and how they would regard me and my position”

- or being close to retirement age (n=1).

“Because I was 63 at the time and within two years of retirement age”

Knowledge of workplace provisions for chronic diseases does not seem to have had much impact on employees’ anxiety levels, as a chi-square analysis suggests no significant impact.² However a moderate correlation *was* observed between delays reported in informing work of a cancer diagnosis and overall rated concerns about job security.³ It therefore appears that employees who delay advising their employers for more than one week about their cancer diagnoses are likely to be fearful of their job security. Under such circumstances, the advice to employers would be to provide particular reassurance about job security to the employee, if they are at all able to do so.

A large majority of employees (n=53; 88.3%) stated that *if* they had requested some privacy surrounding their cancer diagnoses, then their employer had respected this wish. The survey asked no separate question to employees about *whether* they had actually asked for privacy and the double-barrelled nature of this question means that we cannot necessarily infer that a similar proportion of employees actually wished for strict confidentiality surrounding their cancer diagnosis, merely that they perceived their employer to have been discreet and perhaps supportive. A single employee responded that her wish for privacy had *not* been respected by her employer, but her open-ended comments make no mention of this and are positive towards her employer suggesting she

² $\chi^2(1)=1.690; p=.194$

³ $r(59)=.548; p<.001; R^2=29\%$

may have made a clerical error in responding to the item. All employers suggested that their workplaces were well equipped to respect such wishes to either a great extent (n=15; 75.0%) or fair extent (n=5; 25.0%).

3.2.2 Informing Work Colleagues

A majority of employees (n=37; 61.7%) said they informed their work colleagues of their cancer diagnoses straightaway, and just over half of the remainder (n=11; 18.3%) stated that they informed their colleagues within the first week. Very few employees (n=2; 3.3%) suggested that they informed their work colleagues about their cancer at no stage. Most employees (n=34; 56.7%) suggested that they first informed their close colleagues about their cancer and then let others know more gradually over time, but a sizeable proportion (n=20; 33.3%) preferred to tell their close colleagues and ask them to inform others. In general, it appears that employees were not particularly concerned about how colleagues found out of their diagnosis.

“I was happy to discuss my condition with interested work mates”

Indeed, the focus group participants described informing their work colleagues about their cancer diagnosis as a positive, in that it fostered a great deal of well appreciated support from colleagues.

“Telling all my work colleagues that I had cancer facilitated the journey by enabling them to support me”

3.3 Continuing to Work

Of employees who responded to the survey, two-thirds (n=40; 66.7%) stated that they continued to work while undergoing treatment. A large majority of carers (n=17; 94.4%) also suggested that they continued to work. The twenty employers who responded to the survey could collectively recall forty instances of employees developing cancer, and of these, almost all (n=38; 95%) continued working after their initial diagnosis, most (n=32;

80%) continued working during their treatment, and almost all (n=36; 90%) continued to work after their treatment. These data suggest that a majority of cancer sufferers and carers continue to participate in the workforce, at least to some extent, throughout their cancer experience, and that the workplace is a significant feature in the journeys of many cancer sufferers and their carers.

3.4 Importance of Continuing to Work

All focus group participants agreed that it was important to maintain as much of their normal daily routines as possible while undergoing treatment for cancer and that continuing to work was an important aspect of this. The opportunity to continue working while undergoing treatment was described as “mentally cathartic” in that employees were able to immerse themselves in their work as a form of distraction from the ongoing concern about their cancer diagnosis and treatment.

“Whilst receiving treatment it was very important to me to keep working – to focus on something other than myself”

“My time at work was a great distraction from the illness and treatment”

“I was happy to still be working and having that to focus on rather than thinking of my illness”

It also allowed them to retain a sense of being useful and productive.

“Having all this sick leave has left me frustrated and being inactive has made me want to go back to work - being frustrated and inactive annoyed me”

One focus group participant valued coming to work so greatly that he made an “excellent arrangement” with his employer to allow his home cancer treatment service to come to his place of employment and administer his treatment in a specially assigned room. Other participants in the focus group actually expressed their envy at such an arrangement.

Several employees also suggested that work colleagues did not necessarily understand the importance of continuing to come to work. One described how well-meaning colleagues who had just learnt of her cancer diagnosis asked her “*what are you doing here?*” under the assumption that she would automatically stop working as soon as she had learnt of her cancer diagnosis. However the three managers all appeared to appreciate the importance of continued participation in the workplace.

“The employees want to keep coming to work to instil some sense of normalcy”

All of the employers related anecdotes of employees with cancer continuing to come to work even though under absolutely no obligation, financial pressure, nor managerial coercion to do so. One of the employers described an employee continuing to come to work until within weeks of finally succumbing to cancer.

“Some want to keep coming to work even to the ‘last’ ”

3.5 Impact on Work

A large proportion of employees (n=47; 78.3%) and carers (n=16; 88.9%) stated that their cancer experience had impacted on their working life in some way. Equal proportions of employees and carers who did *not* quit their job stated that their cancer experience had impacted on their job as those who had quit.⁴

3.5.1 Negative Impacts on Performance

Of those employees who claimed to have experienced an impact on their working life, just over half described negative impacts (n=26; 43.3%). The majority of these referred to a diminished physical or mental capacity that affected their job performance (n=16). The focus group participants described that while undergoing cancer treatment they became easily tired both physically and mentally, and were well aware that this was impacting on their work performance. The mental impact included memory loss and a phenomenon referred to by some of the participants as “chemo fog”.

⁴ Employees: $\chi^2(1)=.002$ $p=.962$. Carers: $\chi^2(1)=3.445$ $p=.216$

“I had ‘chemo fog’ where I just couldn’t think. This was a real problem at work”

“I found it very difficult to concentrate: memory lapses and fatigue made working full-time almost impossible at first”

Of the twenty employers who responded to the survey, just under half (n=8; 40.0%) believed that the cancer experience affected the ability of their employees to perform the essential functions of their jobs. The wording of this question does not preclude the cancer experience affecting the performance of employees to at least some extent, so a far greater proportion is likely to have had at least some diminishment of their performance. By way of example, one of the interviewed employers described partial performance deterioration in an employee undergoing treatment:

“The treatment had a significant impact on his work; perhaps a 5-10% deterioration”

3.5.2 Financial Impact

Other negative aspects mentioned by employees (n=10) mainly related to both the short-term and long-term economic impact.

*“Getting cancer destroyed my career and forced me to live on DSP
(disability service pension)”*

*“I had a loss of wages; I took six weeks off work so I did not have enough sick leave
to cover time off”*

“Financially it has been a difficult struggle to survive on sickness benefits”

“If poverty is positive then that is the impact”

3.5.3 Positive Impacts

Of those employees who claimed to have experienced an impact on their working life, nearly as many mentioned positive impacts (n=21) as those who mentioned negative

ones. Many mentioned having some form of epiphany about their priorities in terms of work versus personal life (n=11).

“Work has always been a high priority however since my cancer I have re-evaluated the priorities that family and my wellbeing are now a high priority”

“Has made me realise to slow down a bit more”

“Previously I was a workaholic. Now I’ve slowed down to enjoy life and ‘smell some roses’ - more important things to life than the job”

“I have now been called 'inspirational' due to my positive attitude”

Enjoying the support of employers and work colleagues was also frequently mentioned as a positive impact (n=10).

“It has made me realise that I work with a group of caring and supportive co-workers and management”

3.6 Supportive Work Environment

Respondents to the employee survey gave an average rating of 8.8 out of 10 (range 1–10) for the flexibility and support provided by management and 9.3 (range 5–10) for support provided by colleagues. Similarly respondents to the carer survey gave their employers an average rating of 8.1 (range 1–10) for the flexibility and support and their colleagues an average rating of 8.9 (range 4–10). Almost all respondents to the employee survey also suggested that their employees with cancer were ‘greatly’ supported, with the exception of one respondent who said that such employees were ‘fairly’ supported.

3.6.1 Work Adaptation

The majority of employers (n=14; 77.8%) suggested that adaptations were made for employees diagnosed with cancer to continue working. The three interviewed employers felt that any workplace policy covering the issue would have to be extremely

broad, as they stressed flexibility was the key issue, with a need to deal with each on a case-by-case basis. The three employers described making allowances for performance deterioration in a variety of ways. They appointed other staff to assist the employee with cancer:

“We put someone in her role to fit around her needs”

The employers even described picking up some of the workload themselves.

“Another senior colleague and I were determined to carry him ‘come what may’ ”

The employers also noted that work colleagues were quite willing to provide assistance.

“Teams make allowances for colleagues with cancer”

“Other staff don’t mind putting in a little bit of extra effort to compensate”

Many employees gratefully reported being offered a variety of flexible working arrangements by management. Accommodations included switching from full-time to part-time employment, providing relief staff to cover their position, additional paid leave, and additional unpaid leave. One of the interviewed managers and two employee survey respondents suggested that mentoring from previous cancer survivors within the workplace was also very effective.

Not all respondents reported getting support from their employers. A modest proportion of employees and carers (n=9; 15% and n=5; 27.8% respectively) felt they were treated unfairly or unsympathetically by their employers. All of the employees were female, six were full-time employed and three were part-time or casual. Unsurprisingly, they rated their employers as significantly less flexible and supportive than other respondents (mean=5.2/10 vs. 9.4/10 respectively),⁵ but rated the support of their colleagues just as highly (mean=9.4/10 vs. 9.3/10 respectively). Of the five carers, two actually rated their employers 10 out of 10 for flexibility and support, and one rated her employer as a 9 (the other two gave ratings of 1 and 2 out of 10). These contradictions

⁵ $t(58)=-6.419$ $p<.001$

may indicate clerical errors were made, or that the respondents were referring to single instances of unsympathetic behaviour.

In discussions of unfair or unsympathetic behaviours of employees, one focus group participant stated that she was refused the option of part-time work and several survey respondents suggesting that they were either overlooked for promotions (n=5), forced to accept part-time employment or less shifts (n=4), and/or experienced outright job losses (n=2). A few respondents (n=3) even said that their managers had asked for their resignations, and one described being asked to re-apply for her own job while on leave. Unfortunately no other information was available about the kind of industries or workplaces that these employees worked in to establish a pattern.

It appears from these data that the majority of workplaces are highly supportive of staff who develop cancer, and that workplace discrimination related to cancer treatment is the exception rather than the rule. However these data clearly indicate that such *does* exist.

3.6.2 Emotional Support

It appears that the biggest benefit most employees gained from their employers and colleagues was not in regards to work related assistance, but rather to emotional support provided throughout the cancer ordeal. One of the managers pointed out that co-workers often form an important part of a cancer sufferer's social support network which is maintained if they continue to come to work.

“co-workers provide a very important social network which is lost if they stop coming to work”

Employees stressed the importance of this social network while undergoing treatment for cancer.

“My employer and colleagues are the reason I coped so well this year”

“Overall my workplace was my biggest support”

“The constant support [from work] has been a magnificent element in sustaining me”

“During this time I have had complete support at work – so much so that work has become my ‘security blanket’ ”

3.7 Impact on Other Staff

During the interviews, all three employers commented that the impact on other staff also needs to be considered when an employee is diagnosed with cancer. One suggested that it is fairly common for people to have experienced personal tragedies related to cancer and news of a colleague being diagnosed with cancer might conjure painful memories. One of the employers noted that his organisation’s Employee Assistance Program provided a counselling service that was “ideal” for the employee and his or her family, but it had no provision for providing counselling to other staff, which was either left up to the manager, or ignored.

Another employer suggested that it was a natural human reaction for some work colleagues to want to...

“do something, anything, as they feel helpless and impotent to make things right”

One of the employees mentioned this also:

“some colleagues find it very difficult to deal with [my cancer] as they have no way to help control it – they have a feeling of being useless because the biggest support is that they can listen”

The employers suggested that it was useful to channel such feelings into some form of constructive action. Examples of this included sending flowers, cards, visits in hospital, telephone calls, meals cooked, provide transport to treatment, or donating money. These gestures are evidently appreciated by those with cancer, as described by one employee:

“I will never forget my hospital room – it was covered wall to wall in cards, flowers, potted plants, fruit and an Easter bunny”

One particularly notable action that the focus group participants thought was a “brilliant idea” was for colleagues to donate some of their sick leave to a pool for the employee with cancer.

One of the managers also suggested that it is very important to demonstrate the organisation’s compassion to sustain morale.

“Support from management is vital for not only the sufferer, but also the morale of other employees”

The employers reported that other staff wanted to know a lot more about the cancer. It was suggested that a very useful and effective strategy was to brief staff about the nature of the cancer, prognosis, likely treatments and duration, and side effects such as fatigue and memory deterioration. However the information does not need to be overly detailed: a brief overview is usually sufficient with advice as to where staff members can access further information if they wish. Knowledge about the cancer is likely to make colleagues more comfortable around the employee with the cancer, and even encourage them to enquire as to the progress of treatments, which most cancer sufferers say they do not mind, and even appreciate.

3.8 Leave Entitlements

A majority of employees (n=36; 60.0%) suggested that they were unaware of their employers’ policies on leave provisions that they could use concerning chronic disease. Of these only around half (n=15) said that they did find what their leave provision entitlements were. Similarly, around half of carers (n=11; 61.1%) stated they were unaware of leave entitlements in relation to their loved one’s cancer condition and only around half of these (n=6) eventually found out.

However, the focus group participants described suffering “information overload” when they were first diagnosed with cancer, and suggested that in the early days they only needed to have major financial concerns allayed by being assured by their employers that they “would not be stranded”.

“At that stage I didn’t really know what my rights were but felt little need to find out”

One of the employers recommended approaching the discussion of entitlements with “when you’re ready to talk about it”. Another recommended assigning a human resources case manager to the employee who can answer all their questions at once, rather than having to “get back to you on that”.

4 Conclusion

There are little previous data to suggest the impact on employment of individuals undergoing cancer treatments or their carers. The low response rates to the surveys and small number of follow-on consultations must be acknowledged as a limitation of the present study. Therefore response bias cannot be ruled out and the present data should be considered suggestive only. With this caveat in mind, of the cancer sufferers responding to the survey, two-thirds stated that they continued to work while undergoing treatment, suggesting that the workplace is an important factor in the journeys of many cancer sufferers. Nine-in-ten carers suggested that they too continued to work. Fortunately, a large majority of respondents from both of these groups suggested that they felt at no time they were treated unfairly or unsympathetically by their employers. We might therefore tentatively assume from these data that workplace discrimination related to cancer treatment is the exception rather than the rule. What has been highlighted by these consultations is the important role the workplace can have in facilitating the cancer journey of sufferers, by providing a mentally cathartic semblance of continuity while their cancer treatment progresses, and ongoing exposure to the social support networks provided by co-workers.

4.1 Recommendations to Employers

1. When first informed by an employee that he or she has been diagnosed with cancer, reassure the employee of his or her job continued job security, especially if he or she has delayed informing you of the diagnosis.
2. Discussion of sick leave provisions and other entitlements need not be made with the employee immediately, unless this information is requested by them. At this early stage the employee is likely to be feeling somewhat overwhelmed and suffering from ‘information overload’ already. For this reason the “when you’re ready to talk about it” approach is recommended. When the discussion does take place, it is recommended that a case manager is assigned who can answer all questions, such as a human resource manager.

3. If possible, the employee should be offered counselling via an employee assistance program, and this offer should be extended to immediate family members also.
4. Be as generous as the organisation can afford and offer as much flexibility as possible, in terms of offering the employee to work as much or as little as they wish. Do not assume that the employee should stop work - many people with cancer report that continuing to come to work helps them focus on other things than their health, and maintains important social contact.
5. An employee's desire for privacy should always be respected and their wishes as to whether or not they wish for their work colleagues to know about the diagnosis should be clarified. Most employees do not seem to mind if their work colleagues know about their diagnosis, and previous cancer survivors suggest that it can be highly beneficial for work colleagues to know, as it allows them to be supportive.
6. If there is someone else in the office that has previously survived cancer, a highly effective strategy can be to ask them to take on the role of a mentor to the newly diagnosed employee.
7. The reaction of other staff members to the news should also be taken into account, as it can affect people in a large variety of ways. If possible, staff should be offered counselling if they feel they need it, although this is usually beyond the scope of normal employee assistance programs.
8. The desire of other staff to help a colleague diagnosed with cancer can profitably be channelled towards some form of appropriate supportive gesture, such as cards, flowers, gift baskets, donations of money or sick leave, etc. Although colleagues might have a sense of hopelessness, assure them that their expressions of concern and offers of support to the cancer sufferer will be highly appreciated and beneficial.
9. Staff members with no previous experience of cancer are unlikely to have a great deal of knowledge about what lies in future for their colleague. Providing them with information about the type of cancer, prognosis, likely treatments and duration, and side effects such as fatigue and memory deterioration can therefore be a useful strategy. However the information does not need to be overly detailed: a brief overview is usually sufficient with advice as to where staff members can access further information if they wish. Knowledge about the cancer is likely to make

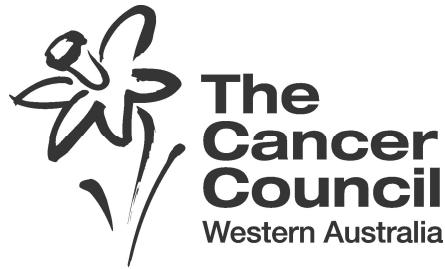
colleagues more comfortable around the employee with the cancer, and even encourage them to enquire as to the progress of treatments, which most cancer sufferers say they do not mind, and even appreciate.

5 Appendices

Appendix A – Employer Survey (6 pages)

Appendix B – Carer Survey (9 pages)

Appendix C – Employee Survey (9 pages)



**EMPLOYER SURVEY
IMPACT OF CANCER IN THE WORKPLACE**

**All information on this form is anonymous and confidential. We have no way of identifying the employer from the responses so please feel free to answer openly.
WHERE APPROPRIATE PLEASE TICK YOUR RESPONSE**

- 1. Type of industry?**
- Health
 - Business
 - Mining
 - Manufacturing
 - Construction
 - Retail
 - Hospitality
 - Small business
 - Government
 - Other _____

2. Approximately how many employees do you have? _____

- 3. To your knowledge, have any of your employees had cancer?**
- Yes
 - No- Go to Question 8

If yes, how many? _____

3b. For each employee, what type/s of cancer were they diagnosed with?

- May tick more than one box*
- Breast
 - Prostate
 - Lung
 - Skin
 - Bowel
 - Other _____
 - Don't Know

3c. How many individuals continued to work after diagnosis? _____

3d. How many individuals continued to work during treatment? _____

3e. How many individuals returned to work after treatment? _____

4. In general, did their cancer experience affect their ability to perform the essential functions of the job? Yes No

If yes, please explain _____

4b. Were accommodations made to assist them in continuing to work?

Yes
 No-go to question 5

If yes, what types of accommodations were made to assist them in remaining at or returning to work? _____

5. Please rate the **GENERAL** supportiveness of co-workers toward the employee dealing with cancer:

- Greatly supportive
- Fairly supportive
- Somewhat supportive
- Not very supportive
- Unsupportive

6. Did you notice feelings of resentment among co-workers towards the person having the cancer experience?

Yes

No-go to question 7

If yes, please describe _____

6b. How did you manage this challenge? _____

7. Please rate the **GENERAL** supportiveness of the supervisor toward the employee with cancer:

- Greatly supportive
- Fairly supportive
- Somewhat supportive
- Not very supportive
- Unsupportive

If unsupportive to any degree, please describe why _____

8. Has your organisation conducted any cancer related education/training?

Yes

No-go to question 9

If yes, in what form(s):

Cancer Support Services e.g. counselling

Cancer related education

Referrals to cancer related services.

Training for managers and employers

other _____

9. To what extent is your organisation currently equipped to undertake the following:

Discussing an employee's preferences concerning their cancer and how their cancer experience is dealt with in the workplace?

Not at all

Small extent

Fair extent

Great extent

If unable to any degree, please describe why _____

Respecting an employee's wishes in regard to maintaining confidentiality if requested by the employee?

Not at all

Small extent

Fair extent

Great extent

If unable to any degree, please describe why? _____

Providing work accommodations such as flexi-time, job restructuring and/or leave of absence for your employees throughout the duration of their cancer experience?

- Not at all
- Small extent
- Fair extent
- Great extent
- Other-please describe _____

If unable to any degree, please describe why _____

Providing counselling or cancer-related information for the employee and the co-workers that are affected by cancer in the workplace?

- Not at all
- Small extent
- Fair extent
- Great extent

If unable to any degree, please describe why _____

10. When are/were your policies on leave entitlements and benefits explained to your employee(s)?

- During induction
- After their diagnosis
- Not at all
- Don't have any

11. Would these policies on leave entitlements and conditions apply to an employee *caring* for a loved one diagnosed with cancer?

- YES
- NO

Please indicate which loved ones would be included under your policy:

- Partner
- Parents of the employee
- Children
- Friend

12. Does your organisation currently have an induction process that describes the organisation’s polices regarding:

- Please tick the boxes that are included in your induction process*
- Flexible working hours
 - Leaves of Absence
 - Employee Assistance Programs
 - Other _____
 - No induction process

13. Please include any additional comments you would like to make concerning your experience with cancer in the workplace or your readiness for handling cancer in the workplace.

THANK YOU VERY KINDLY FOR TAKING THE TIME TO COMPLETE THIS SURVEY



THE IMPACT OF CANCER ON THE WORKING LIFE OF A CARER

All information on this form is anonymous and confidential. We have no way of identifying you or your employer from your response so please feel free to answer openly.

WHERE APPROPRIATE PLEASE TICK YOUR RESPONSE
PLEASE PRINT WRITTEN RESPONSES

1. Gender Male
 Female

2. Age Please tick specific age category

18-25 26-30 31-40 41-50 51-69 70+

3. What type of cancer was your loved one diagnosed with?

- Bowel Cancer
 Breast Cancer
 Lung Cancer
 Prostate Cancer
 Melanoma
 Non-Hodgkins Lymphoma
 Other _____

IMPACT ON WORKING LIFE

4. At the time of your loved one's diagnosis were you in paid employment?

YES
 NO

If yes, was this: full-time part-time casual shift work
 other

5. While your loved one received treatment did you continue to work?
 YES
 NO

6. Has caring for your loved one with cancer had an impact on your working life?
 YES
 NO

If yes, please describe the positive impact _____

And/or the negative impact _____

7. Did you at any time feel your job security was threatened by the fact that you cared for a loved one with a cancer illness?
 YES
 NO

If yes, please describe _____

8. Did you tell your employer about your caring for a loved one with cancer? YES
 NO

If no, why? (then go to Question 16) _____

9. After telling your employer about your caring for a loved one with cancer, did you at any time feel you were treated unfairly or unsympathetically by your employer?

YES
 NO

If yes, please describe: _____

10. How long did you wait to tell your employer about your situation?

please tick a box (A) Did not wait- told immediately
 (B) Within 1 week of cancer illness
 (C) Between 1 week and 1 month
 (D) More than 1 month after cancer illness
 (E) I resigned or did not return to work

11. Were you anxious or nervous about telling your employer of your situation as a carer? YES
 NO

If yes, why? _____

If no, why? _____

12. At the time of telling your employer about your caring for a loved one with a cancer illness, were you told of your employer’s policy on any leave provisions that you could use?

- YES
- NO

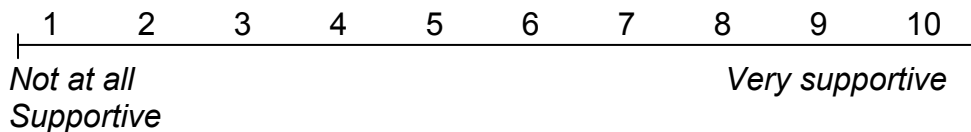
If yes, what did these involve? _____

If no, did you find out later that there were leave provisions available to you?

- YES
- NO

13. How flexible and supportive was your employer concerning your responsibility as a carer?

Please mark your experience on the line



Please describe how your employer provided support or did not provide support as indicated on the line above.

14. If requested, did your employer respect your right to privacy as you cared for your loved one?

- YES
- NO

If no, please describe how your privacy was breached _____

15. Were there any support systems put in place to assist you in managing your work load while you cared for your loved one with cancer?

16. To your knowledge, has your workplace participated in any cancer education?

- YES
- NO

If yes, was this education presented:

- Before your experience with cancer
- During your experience with cancer
- After your experience with cancer

In what form was this education:

- Seminars
- Programs
- Courses on cancer prevention
- Other _____

16b. Have any of your workplaces since your cancer experience participated in cancer education?

- YES
- NO

If yes, in what form was this education:

- Seminars
- Programs
- Courses on cancer prevention
- Other _____

YOUR CO-WORKERS' RESPONSE

17. How long did you wait to tell your co-workers about your situation of caring for a loved one with cancer?

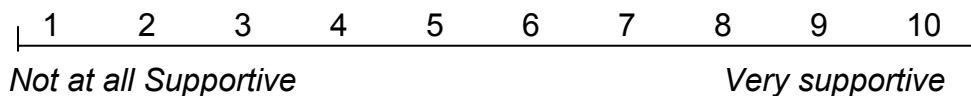
- please tick a box
- (A) Did not wait- told immediately
 - (B) Within 1 week of cancer diagnosis
 - (C) Between 1 week and 1 month
 - (D) More than 1 month after cancer diagnosis
 - (E) Did not tell (Skip to Q19b)
 - (F) I resigned or did not return to work

17b. Who did you tell?

- (G) Told close co-workers immediately but others over a period of time
- (H) Told close co-workers immediately and got them to tell everyone else
- (I) Other _____

18. How supportive were your co-workers concerning your situation?

Please mark your experience on line



Please describe how your co-workers provided support or did not provide support as indicated on the line above.

19. Did you at any time feel that you were treated unfairly or unsympathetically by your co-workers?

- YES
 NO

If yes, please describe: _____

19b. If you experienced difficulties with your co-workers, what do you think would have helped to reduce these problems? _____

IMPACT ON CHILD CARE

20. Did you have children at the time of your loved one's diagnosis and treatment?

- YES
 NO

If no, go to Q22

If yes, how many _____

What was the age of oldest child _____

What was the age of the youngest child ____

21. Has your caring for a loved one with cancer given you any problems with child care?

- YES
- NO

21b. If you have experienced problems, what do you think would have helped to reduce these problems? _____

21c. Would subsidised child care have assisted you during your experience with cancer?

- YES
- NO

How would this have assisted? _____

22. Please include any additional comments you would like to make regarding your experience with cancer in the workplace.

**THANKYOU VERY KINDLY FOR TAKING THE TIME TO
COMPLETE THIS SURVEY**

OPTIONAL

If you would like to participate in a focus group and/or a telephone interview that will assist in developing the workplace guidelines, please complete the enclosed, separate consent form detailing your name and telephone number and post it to us in the self-addressed, stamped envelope provided. We hope to see you there.

5. While having treatment did you continue to work? YES
 NO

6. Has your cancer illness had an impact on your working life? YES
 NO

If yes, please describe the positive impact _____

And/or negative impact _____

7. How long did you wait to tell your employer about your cancer illness?

- please tick a box
- (A) Did not wait- told immediately
 - (B) Within 1 week of cancer illness
 - (C) Between 1 week and 1 month
 - (D) More than 1 month after cancer illness
 - (E) Did not tell
 - (F) I resigned or did not return to work

8. Were you anxious or nervous about telling your employer of your cancer illness? YES
 NO

If yes, why? _____

If no, why? _____

9. Did you at any time feel your job security was threatened by the fact that you had a cancer illness? YES
 NO

If yes, please describe _____

YOUR EMPLOYER’S RESPONSE

10. Before or at the time of telling your employer about your cancer illness, were you aware of your employer’s policy on any leave provisions that you could use concerning chronic illness? YES
 NO

If yes, what did these involve? _____

If no, did you find out later that there were leave provisions available to you? YES
 NO

If you did not tell your employer about your cancer illness, please skip to Question 15.

11. After telling your employer about your cancer illness, did you at any time feel you were treated unfairly/unsympathetically by your employer

or supervisor?

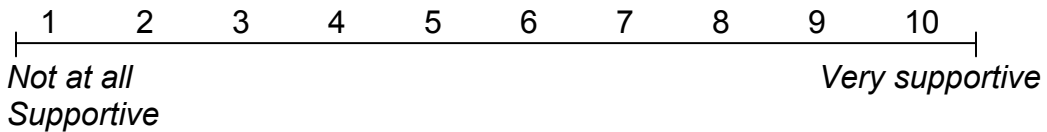
[] YES
[] NO

If yes, please describe: _____

If no, please describe: _____

12. How flexible and supportive was your employer/supervisor concerning your cancer illness?

Please mark your experience on the line



Please describe how your employer/supervisor provided support or did not provide support as indicated on the line above.

13 . In your opinion, could your employer have done anything to improve your working conditions during your cancer experience?

14. If requested, did your employer/supervisor respect your right to privacy regarding your illness?

- YES
- NO

If no, please describe how your privacy was breached _____

15. To your knowledge, has your workplace participated in any cancer education?

- YES
- NO

If yes, was this education presented:

- Before your diagnosis
- During your diagnosis
- After your diagnosis

In what form was this education:

- Seminars
- Programs
- Courses on cancer prevention
- Other _____

15b. Have any of your workplaces since your cancer experience participated in cancer education?

- YES
 NO

If yes, in what form was this education:

- Seminars
 Programs
 Courses on cancer prevention
 Other _____

YOUR CO-WORKERS' RESPONSE

16. How long did you wait to tell your co-workers about your cancer illness?

- please
tick a
box
- (A) Did not wait- told immediately
 (B) Within 1 week of cancer illness
 (C) Between 1 week and 1 month
 (D) More than 1 month after cancer illness
 (E) Did not tell (Skip to Question 19)
 (F) I resigned or did not return to work
 (E) Did not have co-workers to tell (Skip to Q20)

16b. Who did you tell?

- (G) Told close co-workers immediately but others over a period of time
 (H) Told close co-workers immediately and got them to tell everyone else
 (I) Other _____

17. How supportive were your co-workers concerning your cancer experience?

Please mark your experience on line

1	2	3	4	5	6	7	8	9	10	

<i>Not at all Supportive</i>					<i>Very supportive</i>					

Please describe how your co-workers provided support or did not provide support as indicated on the line above

18. Did you at any time feel that you were treated unfairly or unsympathetically by your co-workers YES
 NO

If yes, please describe: _____

19. If you have experienced difficulties with co-workers, what do you think would have helped to reduce these problems? _____

IMPACT ON CHILD CARE

20. Did you have children at time of diagnosis and/or treatment? YES
 NO

If no, go to Q22

If yes, how many _____

What is the age of oldest child _____ and youngest child _____

21. Did/Has your cancer illness given you any additional problems with childcare?

YES
 NO

21b. If you have experienced problems, what do you think would have helped to reduce these problems?

21c. Would subsidised child care have assisted you during your experience with cancer?

YES
 NO

How would this have assisted? _____

22. Please include any additional comments you would like to make concerning your experience with cancer in the workplace.

**THANKYOU VERY KINDLY FOR TAKING THE TIME TO
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OPTIONAL

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