'They don't know what to say or do!'

**A research report on
developing a best practice support model in the workplace
for people with a life-threatening illness
and employed carers.**

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Executive summary

This report on developing a best practice support model in the workplace for people with a life-threatening illness and employed carers is based on research with thirty people and a 100% return rate of university ethics approved signed interview schedules. Of these, nine had a life-threatening illness, seven were employers/managers and five were work colleagues of people with a life-threatening illness, five were employed carers, three were managers and one was a work colleague of an employed carer.

The qualitative research explored the conflicting experiences of identity formed by the meaning assigned to work and illness by Australian culture. For those interviewed, work provided an identity as independent and self-reliant people, able to overcome all that binds and inhibits them. Work enabled participants to be self-centring and self-integrating, determining for themselves whom they will be. Conversely, illness often meant the loss of self-identity for survey participants, experienced as living a restricted life, being socially isolated, living with discrediting definitions of self, and becoming a burden to others.

The conflicting experiences of work and illness caused confusion for many of those surveyed. However, the research interview process created an opportunity for survey participants to shape a narrative of events that supported their construction of meaning in the midst of their confusion. These narratives provided insights into what support had already been marshalled, how effective it was proving, and what other support may be needed. The importance of careful listening became a foundation for the development of a best practice support model for workplaces with either an ill person or employed carer. Three areas stood out as important in support provision for both the ill person and the employed carer.

First, when survey participants disclosed painful or distressing experiences, their story often also disclosed what support they needed, such as a flexible shift roster, social support, time alone, transport, rest breaks at work, physical re-organisation of work space, help with lifting, and succession planning.

Second, embedded in each narrative were the critical factors for that survey participant by which they assessed the support needs for the ill individual or employed carer, supervisors and co-workers, and the work organisation. The needs identified were classified according to their area of management responsibility as either human resource, occupational health and safety, health promoting care, or production needs.

Third, the narratives together reveal both what is unique to each situation, as well as patterns of experience in workplaces. The specific situations and shared patterns of experience point towards the elements of the support process to be considered in best practice models. The interviews reveal that one sequence pattern of support does not fit every situation. How support is provided differs from one workplace to another according to industry, size of the company/organisation, the pressures in the production cycle, the nature and stage of the person's illness, their family circumstances, and the previous experience of all parties with illness, disability and death.

The research identified the following elements of the support process for workplaces employing a person with a life-threatening illness:

1. **Economic support** issues that include income maintenance, the costs and benefits to the company, balancing productivity needs with emotional support, understanding how business needs may submerge personal support options, and the occupational health and safety environment.

2. **Emotional support** issues that include how to deal with a range of tough emotions, understanding how workplaces bury emotions raised by a life-threatening illness, the challenge of sharing emotions at work, the process of becoming emotionally detached from work, and the role of an employer as advocate beyond the workplace.

3. Issues in **information support** that include informing people at work of a person's illness, keeping staff and clients informed, and the place of management training and advice.

4. Issues in **appraisal support** were assigned to one of four psychosocial meanings attributed to illness:
    *   an illness with no significance for work,
    *   when work is a defence against the threat of illness to the person's self identity,
    *   illness as a loss, and
    *   illness as a gain.

The research did not highlight any new issues for employed carers for their emotional, information and appraisal support needs from those needs identified for people with a life-threatening illness. The economic elements of income maintenance for employed carers, and the assessment of the company's costs and benefits were also issues in common with the support needs for a person with a life-threatening illness. The small number of employed carers interviewed means the pattern of responses identified will benefit from further study.

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A SPECIAL ACKNOWLEDGEMENT

Improved Workplace Support for Life-threatening Illness

The model being offered here is only possible because thirty people touched in some way by a life-threatening illness were willing to share their experiences. Often, their motivation for participating in the research was to help others in the future, and in particular, that others may not have to suffer in the same way they suffered. The development of best practice support for Australian workplaces needs others who will use this model in the future to provide feedback and evaluation of their experience.

This then, is not a conclusion, but an invitation to write to Palliative Care Victoria about your experience with the issues discussed in this report. In this way, Australian workplaces may gradually learn what to say and what to do!

All names have been changed in this report to protect the identities of each research participant. John Bottomley and Mary Tehan would like to humbly thank each person who contributed to this original research

Part one

INTRODUCTION

'Don't tell people about your illness'

(Employer to ill staff member)

Introduction

This project initially described its aim as a support model for 'terminal illness in the workplace'. Early experience in the project and informed opinion indicated that ill people in the workplace, their employed carers, employers and work colleagues mostly live in the hope of their recovery. Some in industry said that the topic was "too sensitive". In recognition of this new awareness the aim of the project was changed to a support model for 'life-threatening illness in the workplace'.

The importance of listening to these views is emphasised by the finding of cross-cultural studies that have noted, "Modern physicians diagnose and treat *diseases* (abnormalities in the structure and function of body organs and systems), whereas patients suffer *illnesses* (experiences of disvalued changes in states of being and in social function; the human experience of sickness).[1] While one criterion for being interviewed for this project was on people who had a medical diagnosis of a life-threatening disease, the research focus was on their illness experience in the workplace, and their relationships with others in employment –their carers, employers and work colleagues.

However, changing the language from 'terminal' to 'life-threatening' illness doesn't change the fact that most, if not all of the interviews for this project were conducted under the shadow of death. With death as a possible outcome for any of the diseases with which survey respondents had been diagnosed, the encounter with death looms large, both symbolically and in reality. To talk about a life-threatening illness means in fact it is necessary to consider the reality of the illness experience and its likely links with dying, death, and bereavement.

The experience of illness, including its links with dying, death and bereavement, "is shaped by cultural factors governing perception, labelling, explanation and valuation of the discomforting experience - processes embedded in a complex family, social and cultural nexus."[2] This study considers how the culture of work influences, and is shaped by, interaction with a life-threatening sickness.

There is considerable literature about the place and meaning of illness, dying, death and bereavement in Western industrial societies. The culture of work is central to shaping this sense of place and meaning. The research shows how the reality of people's experience of illness, dying, death and bereavement in the workplace constitutes contested ground for understanding the meaning of what is happening.

The research shows the capacity of many people to continue in the workplace gradually diminishes when they are faced with life-threatening illness. The ill or dying person or their carer often experiences physical, emotional and financial stresses that impact not only on their well-being, but also on work productivity, work relationships and workplace health and safety. This research describes their experiences at work, and reports on how their employers/managers and work colleagues have developed policies and strategies to best support the ill or dying person or carer in their workplace.

The cumulation of this experience will be used to develop a model of best practice for employers and workplaces to support those at work with a life-threatening illness, their carers, and work colleagues. "The term best practice is used here to refer to 'the best way of doing things'."[3] In this report, best practice will combine the findings of the survey with informed opinion from others in this field. Following Renzenbrink, best practice support not only refers to direct involvement of all parties, but "also policy development, program infrastructure and the sequencing of care."[4] Kellehear also draws attention to the importance of policy development alongside practical social support as fundamental tenets of quality support for life-threatening illness.[5]

Methodology

A qualitative methodology was proposed to explore the dimensions of support for those in paid employment with a life-threatening illness or employed carers of persons with a life-threatening illness. The methodology and survey formats were submitted for ethics approval through the University of Wollongong Ethics Committee, the same University that was conducting the national evaluation of the Caring Communities Program. Appropriate procedures were put in place to protect the confidentiality of participants, ensure the validity of interview records, and ensure the psychological well-being of survey participants post-interview.

Information was circulated through a range of organisations including the following and participation was invited:
- an employer body (Victorian Employers' Chamber of Commerce and Industry);
- palliative care networks;
- Divisions of General Practice;
- support organisations for various life-threatening illnesses;
- hospitals;
- Government Departments.

Much work went into informing various groups and organisations about the project to raise awareness about the research element of the project in particular and to invite participation. The Project Officer followed up workplaces that expressed interest and posters advertising the research element were distributed for their noticeboards.

Potential participants volunteered to be interviewed, with the researchers conducting the interviews at a convenient location for each participant. A quota sample of 30 interviews was obtained, with quotas determined across a spread of industries, small, medium and large in size, and public and private sector employment. 100% return rate of signed interview schedules was achieved. Interviews ranging from 40 minutes to two hours were carried out in metropolitan Melbourne, rural and regional Victoria, and three in Sydney.

Four interview schedules (see appendices) were designed for:
- a person with a life-threatening illness (10 respondents);
- the manager of the ill person and/or a work colleague (11 respondents – 6 managers of the ill person, 5 work colleagues);
- a carer of a person with a life-threatening illness (5 respondents);
- the manager of the carer and/or a work colleague (4 respondents – 3 managers of carers, 1 work colleague).

Within a week or two of their interviews being completed each respondent was mailed a draft copy of the written report of their interview for them to validate, sign and return as an accurate/corrected record. This process became an important means of de-briefing the interview experience, providing further fruitful data.

Survey participants

The following tables summarised employment information about the survey participants, and in the case of those with a life-threatening illness, the nature of their diagnosis.

Table 1:
Employment situation and diagnosis of respondents with a life-threatening illness

Case no.	Industry	Sector and no. employed	Occupation	Years in current employ-ment	Full-time or part-time	Diagnosis
1	Hospitality	Private, 80+	Chef	4	F/T	Bowel cancer
2	Service	Private, 5	Managing Director	12	F/T	Mantle cell lymphoma
3	Freight and packaging	Private, 3	Employer	7	F/T	Breast cancer
4	Education	Private, 30	CEO	6	F/T	Naso-pharyngeal cancer
5	Agricultural science	Public, 150	Agricultural scientist	32	F/T	Motor neurone disease
6	Medical transport	Private, 130+	Ambulance officer	9	P/T	Bowel cancer
7	Health care	Private, 5	Medical receptionist	7	P/T	Breast cancer
8	Agriculture	Private, 1000-1200	Information technology coordinator	22	F/T	Malignant melanoma
9	Legal	Public, 10	Deputy registrar	32	F/T	Motor neurone disease

Table 2:
Employment situation of the employer/manager of a person with a life-threatening illness

Case no.	Industry	Sector and no. employed	Occupation
10	Agribusiness	Private, 1000-1200	Manager
11	Construction	Private, 100+	Supervisor
12	Patient transport service	Private, 135-140	General manager
13	Medical	Private, 5	Employer, manager
14	Legal	Public, 10	Manager
15	Agriculture	Public, 150	Manager
16	Service	Private 5	Employer

Table 3:
Employment situation of a work colleague of a person with a life-threatening illness

Case no.	Industry	Sector and no. employed	Occupation
17	Patient transport	Private, 100+ (regular)	Ambulance attendant
18	Adult education	Private, 30	Advisor
19	Agricultural research	Public, 150-160	Colleague
20	Construction	Private, 120	Office manager/ accounts
21	Freight and packing	Private, 3	Assistant

Table 4:
Employment situation of carers of a person with a life-threatening illness

Case no.	Industry	Sector and no. employed	Occupation	Years in current employment	Full-time or part-time
22	Hospice & palliative care	Public, 70	Clinical nurse consultant	9	F/T
23	Educational services	Private, 20+	Receptionist	1.5	P/T
24	Food wholesaling	Private, 25+	Managing Director	9	F/T
25	Engineering	Private, 120	Projects manager	28	F/T
26	Health care	Public, 500	Nurse	1	P/T

Table 5:
Employment situation of the employer/manager of the carer of a person with a life-threatening illness

Case no.	Industry	Sector and no. employed	Occupation
27	Engineering	Private, 120	Manager
28	Community education	Private, 20+	Supervisor
29	Health care	Public, 500	Nurse Unit Manager

Table 6:
Employment situation of a work colleague of the carer of a person with a life-threatening illness

Case no.	Industry	Sector and no. employed	Occupation
30	Health care	Public 500	Nurse colleague

Work and illness: conflicting experiences of identity

The place and meaning of work in Australian society has a taken-for-granted quality that renders it almost invisible. Commenting on the 2005 Federal budget, Ross Gittins said, "It was written all over last month's federal budget, but nobody could see it. I missed it myself. … Why did everyone miss it? Because it has become so commonplace. … What was it? Work. Work and more work. The budget was obsessed by work. … But this sanctification of work shouldn't be allowed to pass unexamined. I think it is a perversion of what life … is supposed to be about. (The budget assumes) that the only reason we work – the *only* reason – is to get the money we use to buy the things that really satisfy us. … But do you see what's happening?

We're putting the maximisation of production ahead of enjoyment of the fruits of production – time to *enjoy* the stuff we buy, time for leisure and recuperation, time for relationships with family and friends."[6]

Gittins' concern about the lack of balance between work as production and having time to enjoy the fruits of our production is perhaps less important than his critique that the meaning of work is tied to what each person's work achieves for them. This supports Meda's earlier observation that work is "the only means of fulfilling all individual and social aspirations (and is the) . . . main vehicle for the formation of social relationships and for self-fulfilment."[7] The cultural meaning of work in Australian society is its importance as the source of self identity for each autonomous human subject. Those interviewed confirm two aspects to self identity in what work means for them.

Work enables people to be independent and self-reliant, overcoming all that binds and inhibits them.

"It means security, both financially and with relationships." (ill person)

"Work has given me independence after getting out of a bad marriage." (ill person)

"I get stimulation from work and working in partnership with people. Work is a means to the end of providing for my family and my future." (ill person)

"It is important because I am paying off a mortgage. I have worked ever since I was eight years of age. Everything I have I've worked for." (carer)

"Work was always important to me. I do my job as a receptionist as best I can, but I don't think I had any value or worth where I worked." (carer)

Work enables people to be self-centring and self-integrating, determining for themselves whom they will be.

"It's a very important part of my life because I grew up with a protestant work ethic. It has been really interesting, rewarding, exciting." (ill person)

"Work keeps me sane. It is very physical, and keeps my mind and body healthy." (ill person)

"I am part of a team. There is loyalty between my boss and me." (ill person)

"I enjoy helping others reach their dreams and become successful. My biggest strength is relationship building. But I was trying to be all things to all people. I had to prove myself. It is important for me to be recognised or acknowledged. I had this identity." (ill person)

"My work meant a lot to me. I worked hard, and had many rewards, such as travel. Work has been very exciting, frustrating, enjoyable." (carer)

"Work has always been important to me. I keep it balanced in my life. I take a humanist approach to life and business. If you look after people, it will generate business and money." (carer)

"Work was pretty important. I think it defined who I had become. Sadly, my children sometimes came second." (carer)

"I love helping people. I enjoy work and working with my mates." (carer)

If work is the foundation for the construction of self-identity in Australian culture, then the experience of illness is felt as the loss of self-identity. Those interviewed identified up to four sources of the loss of control and action that typify the construction of the sense of self in Australian society.[8]

Living a restricted life

As the illness becomes the focus of the person's life, with its treatment routines, periods of discomfit and pain, medical appointments, and mundane activities filling their day, those with a life-threatening illness may find they have fewer possibilities for constructing valued selves.

> "Once you are diagnosed, you lose control of your life. You are told what you need to do." (ill person)

> "My illness may affect my cognitive ability. I also believe my medication causes sleepiness and dullness. So I have told my wife to let me know if she observes any cognitive impairment. It would interfere with my ability to work. I would be less able to make decisions, and remember things." (ill person)

> "I have been having aches and pains, fatigue, withdrawal of drugs, arthritis in the joints in my fingers, my hair hasn't started to grow, and my finger nails are going to fall off again." (ill person)

> "My illness makes him tired, especially by the end of the week. I have lost strength in my legs and arms. I could fall over and break a bone. I can't lift things." (ill person)

> "After the first year of my wife's illness, I lost confidence. It was like a kick in the stomach to me. I couldn't work well because I was preoccupied. Every day in the next two years, something was happening with her illness." (carer)

> "I was devastated when told my husband had mesothelioma. The oncologist said, 'There is no hope for you.' It wasn't fair. Laurie was too young. It was too hard. We did not have enough time together. We never got to talk about it he died so quick." (carer)

These experiences are valued negatively against the social values of independence and individualism, intensifying the sense of loss of control that results in loss of self. The negative valuing becomes attached to the carer of a person with a life-threatening illness, as well as to the sick person.

Social isolation

Social isolation is a consequence of a restricted life, as social networks break down.

> When David was interviewed he had been on sick leave for 18 months and was missing work. In particular, he expressed his loss of the social relationships he enjoyed at work.

> Peter's disease has affected his voice. "This has been embarrassing for me, especially when dealing with the public. It has also been hard to communicate with work colleagues. While I try to be upbeat at work, I have days when I feel depressed." (ill person)

"Our workers didn't want to see him wither away, so they were relieved when he went on sick leave." (manager)

There were some clients Molly has not heard from since they knew she was ill. "Now I am not sure how I will contact them to renew my business. It is a huge challenge for me to face that. Will I be dealing with their fear of cancer, and then my fear of their projection?" (ill person)

Barb's relationship with head office has been detrimental to her mental and emotional health. "They are scared of the illness. The number of people who have dropped off contact because they are scared of the illness has really rocked me." (ill person)

One CEO was also the ill person. He said, "None of my networks – which are excellent – relate to this illness thing. I feel vulnerable."

Social isolation may be a result of spending time on medical routines, not being physically able to participate in shared activities, or from emotional isolation due to feelings of embarrassment or being ignored, or devalued.

Discrediting definitions of self
The ill person may suffer loss of self when their self definition is discredited, either in interactions with others or from unmet expectations of their own.

An ill person said one of the least helpful things that happened to him at work was one of his bosses saying, "Don't tell people about your illness."

"I will be dead in five years or less, roughly speaking. Ninety-five per cent of the time I feel O.K. about it. I have noticed some new symptoms - a lump in the throat. I can't ignore it or think nothing's happened. Ten per cent of the time I am angry, frustrated and sad." (ill person)

During her illness and treatment, Molly found almost no support for her identity as a business owner within the medical system. "Neither my specialist or the hospital knew what sort of work I did. They didn't ask. No-one asked me what I did!" (ill person)

"When Dave told me I was completely shocked. I couldn't believe it. It was like a death in the family. My neighbour's son was killed in a car accident recently. Dave's news was like that." (manager)

The perceived impact of the discrediting is greater when the ill person feels vulnerable and is forced to accept the discrediting definitions. The impact is also heightened when significant others such as work colleagues do not understand or accept the limitations inherent in the present condition of the sick person.

Becoming a burden

Becoming a burden essentially involves becoming more dependent and immobilised, and faces the ill person with the recognition that their illness has become their major source of identity. Associated feelings are those of being useless to your self and others.

> "It's a hard battle at the moment … it's tough … I just need something to turn it around at the moment." (ill person)

> "I am dying, but I haven't bothered to ask any more about it. I don't want to know more than that. I am not happy about it. It is very distressing. I thought I had come to terms with it, but that reaction took me by surprise. I live each day at a time, and try not to think about it." (ill person)

> "When Darren told me we had a huge argument. He thought we were getting rid of him. He was a tough fella who went down in tears." (manager)

> "Eventually it will get me. I will fight it – I'm giving it a good nudge. My worrying days are ahead of me. It does get to you. It's hard. I am hoping for a miracle." (ill person)

A life-threatening illness represents a dramatic challenge to the meaning of the sick person's self identity established through their working life. Their diagnosis and onset of illness is likely to be a source of profound upheaval, emotional distress, and confusion for the ill person, their carer, and their supervisors and work colleagues.

The confusion of conflicting experiences: listening as a key to understanding

The focus of the research was to better understand these conflicting realities and develop practices to support all parties to manage this challenge and upheaval. It became evident that the survey process itself suggested an initial response that may help equip people to discover their own meaning in the midst of the loss of culturally valued definitions of self.

Several ill people who spoke to the Project Officer while validating their written interview transcripts commented how the interview experience changed their experience of being ill at work. One said how pleased he was the interview was conducted in a safe environment for such personal disclosure. He said, "I was often asked how I was in the corridor. I am glad we didn't do this interview in the corridor."

It appears work often has little or no space or time for dealing with the deeply personal nature of life-threatening illness. One manager wondered why he was telling the interviewer "all these things". The interview helped him realise he had not paid attention to all that was happening due to his staff member's illness, "and this has prompted me to do something about it."

It appears that for many of those employers, work colleagues and ill people who were distressed by the upheaval of a life-threatening illness, the interview experience empowered them to face the future. One ill person said the interview "has been good.

It was cathartic, a release." Another said the interview encouraged them to think about their values, saying, "I do have some faith now that I think about it." A third ill person acknowledged the process helped them "realise I should have stopped work." One who was anxious about being interviewed said "I didn't think this would help, but it has been good."

One manager agreed the interview was empowering, saying "to talk like this with you has helped me sort through the issues, and work out I need to get support." Another manager appreciated the opportunity provided by the interview to reflect upon their experience. For one work colleague, the interview provided an affirmation of what they do to support their colleague, and a reminder of tasks that will follow up their support. Another saw reflected back to her, her competence in caring for others. "This is one way I can help," she said.

These comments are the result of being able to tell the story of their experience through the open-ended nature of the survey process. "We comprehend our lives not as disconnected actions or isolated events but in terms of a narrative. … Stories help us organise and make sense of the experiences of a life."[9]

The research interview created an opportunity for survey participants to shape a narrative of events that facilitated their construction of meaning in the midst of the collapse and disintegration of established structures of meaning.

A best practice model for support of a person with a life-threatening illness in their workplace starts here, with an intervention that:

- creates time and space/place to listen deeply to the chaos ensuing for all those in the workplace affected by the clash of work and illness realities;

- affirms the strengths of each person's way of coping, and accepts their self-declared limitations or fears;

- establishes the diverse and divergent sequencing of support processes for the ill person or carer, and their employer/manager, and work colleagues that are shaped by their respective narrative trajectories. Support for each individual involves:
    - integrating the story-teller's (survey respondent's) past with what they perceive to be happening in the present, and

    - integrating the past and disordered/confused present with what the story-teller anticipates for the future.

Post-interview feedback suggests the non-judgmental nature of the survey listening affirmed various respondents in the essential truths of their experience, and deepened their valuing of the choices and actions they had taken.

Careful listening to these narratives provides insight into what support has already been marshalled, how effective it is proving, and what other support may be needed. Three areas of importance stand out. First, accepting and validating what have been painful or distressing experiences when they are narrated creates trust and security that leads to disclosure of vulnerability, struggle and need. Secondly, reviewing the total fabric of the experience without fear or judgmentalism establishes a framework for assessing necessary areas of support. Thirdly, the narratives reveal both the unique nature of each person's experience, as well as the shared experiences people have of work, illness and support. The shared experiences suggest priorities for policy development for best practice support, while the individual experiences may remind those implementing policies of the importance of their continuous listening, clarifying, collaboration and evaluation with the ill person or carer, and their work colleagues in providing best practice support.

In part two, each of these three important insights into the development of a best practice support model will be considered through the narratives of people with a life-threatening illness, their employers/managers, and work colleagues. Part three will consider the same insights through the narratives of carers of people with a life-threatening illness, their employers/managers, and work colleagues. Part four concludes the report and outlines the Support model.

Part two

BEST PRACTICE ISSUES FOR SUPPORTING A PERSON AT WORK WITH A LIFE-THREATENING ILLNESS

'They need direction'

(Managing Director referring to his employees' response to working with their ill work-mate)

In this part of the report, the three previously identified important insights into the development of a best practice support model will be considered through the narratives of people with a life-threatening illness, their employers/managers, and work colleagues.

Accepting, disclosing

The narratives collected in the research provide an insight into the importance of accepting and validating what have been painful or distressing experiences for the ill person, their employers/managers and work colleagues. The narratives often functioned to create trust and security for the research participant that then encouraged them to disclose significant issues about their vulnerability, struggle and need.

The movement from acceptance to disclosure is thus identified as a key movement for any one seeking to provide support, because it describes the process of listening that is at the heart of discerning how to support people in their vulnerability, struggle and need.

People with a life-threatening illness

The movement from acceptance to disclosure is first explored through the interview responses of three people with a life-threatening illness.

Accepting painful experience	Disclosing then meeting need
Ill person (Paul):	
▪ "I can only work three days per week and keep my disability pension. I let the General Manager know if I am finding it difficult to do a shift. I can take time off."	• "Company works ten hour shifts, but I am only able to work eight hours due to tiredness from illness. Company have offered extra time if I need it."
▪ "I can't lift heavy patients after surgery and with my illness."	• "They roster me with the same people so that helps. I lift each end with my partner for a really heavy patient. This is a safe practice."
▪ "I kicked out my girl friend because she had an affair after I was ill."	• "I have been depressed, but I get good support from fellow workers, especially female workers."
▪ "I wasn't sure how I would go after surgery and was discharged from ICU to a ward. I had no colour, had lost my hair, and lost so much weight."	• "I didn't want to see anyone after surgery. The manager made sure staff knew this."
▪ "I tell the GM how I am coping. He knows about my colostomy. It is a degrading sort of thing."	• "GM said they will do anything they can to support me. I talk about the colostomy so they understand it more. It helps us work well on the day."

This summary of Paul's interview indicates how Paul's disclosure of various aspects of his illness has led to his needs being identified by his manager. The company was able to introduce greater flexibility to his work rosters, ensure his shift partner could work with his physical limitation with lifting, protect his need for privacy after surgery, and provide a supportive environment for his colostomy. Paul's disclosure about his girl-friend's affair has also led to a supportive response from fellow workers, especially his female co-workers.

Accepting painful experience	Disclosing then meeting need
Ill person (Clare)	
• "I am frightened the ovarian cancer may come back. There have been ups and downs. At times I feel I can conquer anything."	• "My boss was incredibly supportive. He said, 'we will get through this, and I was not to worry about my situation at work'."
• "I had allergic reactions to the chemotherapy that put me back in hospital after each treatment."	• "My friends took me to chemo and stayed with me, then brought me home."
• "I had no money coming in and I had no energy to cook. I was not able to do one day of work for eight months. There were times of depression and sadness. I couldn't pay for my two girl's entertainment. My older daughter quit her job to look after me, but then had no spending money of her own."	• "My boss dropped off food for the kids. He has offered counselling to the kids if they need it. They paid me regularly until all my sick leave and holiday pay was used up. Being paid again is helping with my rent. Feeling I am contributing is also important to me. I was overwhelmed they valued me as a staff person. Now I am working my way back to health and independence. At present I am very emotional, rather than depressed."
• "I was very anxious returning to work. I would forget my work routines. I forget things from being over-tired."	• "I can come home for an hour to rest at lunchtime. I need to rest on my days off. I am also working fewer hours at present. I am not pressured to finish everything each day. I know what I can't do will be picked up by the person on the next shift. I appreciate their flexibility to make things work."
• "Because of my surgery, I can't lift or stretch."	• "My boss has shifted all the current files down to a level that is easier for me to reach them. He has refurbished the office to make it easier to work in."
• "When I felt down, and nobody rang to ask how to do the work I had done, that was hard. They wanted to leave me alone, and they thought it was for my own benefit. I wasn't invited to staff meetings while I was ill, and this peeved me."	• "I wanted to be able to say 'no' " (I can't come today).

This summary of Clare's interview indicates how Clare's disclosure of various aspects of her illness has led to her needs being identified by her employers. The company responded by providing emotional support, ensuring payment of leave entitlements, flexibility with return to work rosters and rest, attention to inter-office communication to ensure smooth transitions with staff on other shifts, and a reorganisation of the physical environment to make filing less physically demanding.

Clare's disclosure of her allergic reaction to treatment was during her sick leave, and friends supported her. The one need Clare did not disclose during her sick leave – not being invited to staff meetings – was a source of irritation to her.

Clare's employer's interview clarified that there was a shared understanding between them of Clare's needs in relation to her need for job and financial security, her struggle with tiredness after surgery/treatment and coping with mistakes at work, and the importance of being valued as a good worker and loyal staff member.

Accepting painful experience	Disclosing then meeting need
Ill person (Tim):	
• "I will be dead in five years or less. Most of the time I feel OK about it. I adjust to the facts. My illness may affect my cognitive ability. I can't ignore it or think nothing has happened. Ten per cent of the time I am angry, frustrated, sad."	• "I have told my wife to be aware that I may lose my cognitive ability, and then I'd tell my boss. It would interfere with my ability to work because I couldn't make decisions or remember things."
• "My body is weak. Some things are painful so I don't do them as much. Typing at the computer is difficult. I have reduced strength. I can't do lifting. One area I'm concerned about is carrying bottles and dangerous acids."	• "Other people help with lifting and typing. I have rejigged these things. It is ongoing. I am now avoiding carrying acids. My boss has given me permission to have flexibility at work. We work like that. OHS have provided me with a new desk. There has been a 'physio' assessment of the workplace. I can get a voice recognition computer program" (to replace typing).
• "I intend to resign at the end of the year, when I am fifty-five and can collect my superannuation. I told my higher up bosses I had a health problem, not a terminal illness because they would treat me like a lame duck from then on."	• "I have been open about this at work. It can be a risk to be open, but I have respect and credibility, and my boss has protected me before. I have credibility with the funding body that granted us a three-year project. I told them, and they said it is OK, with some timelines agreed. When my boss had to tell his bosses, he was going to give a woolly reason, but I said to be truthful."
• "I am not going to be around here forever."	• "By telling people about my illness, they can help me, and they can then take over when I'm gone. In terms of succession planning, a person is now helping one day per week on my funded project. I saw the importance of this."

This summary of Tim's interview indicates how Tim's disclosure of various aspects of his illness has led to his needs being understood by his management. The organisation responded by providing support to Tim with lifting and typing, accepting

the need to change some of his work tasks, provision of a new desk to meet OHS requirements, an assessment of the work environment by a therapist, modification of work equipment so Tim can continue to work, renegotiating contractual obligations, and succession planning for carrying on his work. All these responses to Tim's needs in this large public sector organisation appear to address his personal needs almost exclusively through organisational and technical strategies.

Employers/managers of a person with a life-threatening illness

The movement from acceptance to disclosure is next explored through the interview responses of three managers/supervisors of people with a life-threatening illness.

Accepting painful experience	Disclosing then meeting need
Manager (Jarrad):	
• "I mentioned a friend's cancer to David, and then David told me of his illness. I was very affected by the news as I had a developing friendship with him. He was very important to our work because he maintained all the computers in his region."	• "I arranged for Nic, the other staff person to cover David's work and his own. The drought meant there was a smaller harvest, so Nic was able to cope. We supported David's identity as an important team member. "
• "The father of the other person working in the region was also battling with cancer. It was high maintenance and took prioritising."	• "I had to make do. Upper management told me how to deal with it by spreading the load. We all had to help, and we re-jigged some work responsibilities in our team. The experience has strengthened some relationships and interactions between direct members of the group."
• "I tried to remain positive with David, so there was no staff training about managing his illness while he was working."	• "I tried to keep the status quo until he recovered and returned to work, but he never came back from sick leave, and died. This has focused attention on our mortality. A lot of people feel strongly the impermanence of life."
• "He took a lot of time off for surgery and treatment."	• "The company put on a benefit concert for him, which gave him an opportunity to attend a lifestyle camp."
• "The loss of David's experience has slowed down our work. Others don't have the experience he had. Delays have been constant."	• "He only came back on odd days. He self monitored and went home if he was tired. We didn't have experienced people we could bring in to work with him."

This summary of Jarrad's interview indicates how Jarrad's awareness of various aspects of his employee's (David) illness has led to the different needs of David, other staff and the company being understood and addressed by Jarrad.

After the shock of David's news about his cancer, Jarrad arranged for the company's production needs to be covered while endeavouring to support David's need to maintain his identity as an important team member. Jarrad clarified his authority to

act with his management, then reallocated David's work and spread the load of work responsibilities across his team. Reduced production demand assisted this process. Perhaps an unanticipated benefit was the strengthening of relations across the team.

Jarrad's decision to be 'positive' with David meant the fact David was dying was ignored until after he died. There was no staff training around managing the illness, so David's death raised questions for some about what they valued in life. Perhaps the strength of feeling amongst staff about their mortality could be attributed to not facing these tough feelings more openly during David's illness. It is possible the constant production delays were also influenced by the apparent fear of accepting David's dying. There was no succession planning, so David's twenty-two years of experience in the industry was lost to the company.

Accepting painful experience	Disclosing then meeting need
Manager (Terry):	
• "It was physically obvious Peter was ill. When he told me, I felt shithouse. Then I began to think, 'What do we need to do?' He didn't want to tell other staff, just for me to speak quietly to a few of his close colleagues. They began asking me what was wrong with Peter."	• "Peter told me after tests confirmed his illness. After about four months, I told the staff of Peter's illness. He asked to be absent that day. When I told them at first there was shock. I explained how I would manage Peter, and what I expected of them. They now see it as a shared task. I was given advice by our HR department on privacy issues and what I could do for Peter at our workplace. My manager agreed I am responsible for managing this situation. This has been very helpful – an acceptance I have the capability to manage the situation. I looked at a video about Peter's illness, and it helped me greatly. I showed it to Peter and his wife, which was emotional. We talked about it a few days later. I have asked the support worker from a specialist organisation to talk with my staff about his particular illness. The workplace supports and resources whatever staff training I need. It is good Peter is not hiding from it, and he will talk with staff about his illness if they ask."
• "Peter has carried out a specialist job in our organisation for twenty years. He is invaluable. He cannot use his right hand any more for writing."	• "He has not lost any mental faculties, and can still do the theory part of his work. I have arranged with him to take on a supervisory role. I have dedicated one of our staff to work with him. She helps him with physical tasks, and he provides her with on-the-job training. This addresses the future loss of his experience. It meant losing one person from another area, and others have had to work harder in her area to cover her work there. The team has accepted this. The rehabilitation people came in to give advice on his workplace environment. I have changed Peter's computer, and made modifications to other equipment, such as the phone and the security system for opening doors. He has permission not to wear a tie (dress code for work) because it hurts his throat."
• "Recently the deterioration of Peter's speech has made communication difficult. He is struggling to talk with our clients."	• "I have advised clients who deal with Peter of his condition, and advise them how to treat him. They come back to his assistant or other staff to check they have communicated correctly."

- "He is becoming tired at work. His illness is affecting his ability to work safely because of reduced mobility and slower reaction times. Also, this frustrates him."

- "I have a mate's agreement with Peter about him continuing at work. We will manage it between us. I have told him if he is tired not to come to work and he will not lose pay for any time off. I have asked him to tell me what he wants. I believe he will tell me when he can no longer work. I keep him away from counter work, which can be stressful. But his attitude to work has not changed. He wants to know what is going on. He cares about issues and work colleagues. Also, he is showing others you can work with a disability. He helps others put their problems in perspective. That shows guts on his part."

- "An older staff member who has had a long association with Peter is not coping well with his illness. Her husband died two years ago. I see her being upset."

- "I am not sure what to do with her. I am not sure how to support her. Her work hasn't suffered."

- "Sometimes I feel frustrated by his illness. We didn't have a succession plan for doing his work. I worry more about him when I am on the road away from the office. He is a close personal friend. I wasn't sure how much I could tell my wife because of privacy issues. I was a bit moody and touchy."

- "His illness has also made me look more at my people management. I am more conscious of what my people are doing, and how they are dealing with the pressure."

This summary of Terry's interview indicates how Terry's awareness of various aspects of his employee's (Peter) illness has led to the different needs of Peter, other staff and the organisation being understood and addressed by Terry.

Terry and Peter draw upon a long-standing work relationship and friendship. Terry takes responsibility for managing the issues arising from Peter's illness, provides personal support as he is able, and trusts Peter to inform him of how Peter's illness is affecting him. Peter agrees that the way Terry has gone about being informed about Peter's illness, and exploring the HR implications has strengthened their relationship. Their experience underlines Altschuler's belief that "despite the urgency of the possibility of death", it is important that the issues are worked through in consultation with the ill person at a pace that feels safe for all parties. It is important to create space for each person to gain some understanding of their responses so they are able to "redefine their connectedness, and retain agency, competence and integrity."[10]

Terry kept Peter's confidence about Peter's diagnosis until Peter advised how he would prefer the matter dealt with. In that time, Terry researched Peter's illness with a specialist support organisation, clarified his authority with his manager regarding

dealing with Peter and his staff team, and took advice from the organisation's Human Resources Department.

This gave Terry confidence to be proactive with:

- Peter - organising to inform staff of Peter's illness, arranging to show a video to Peter and his wife, organising rehabilitation assessment of the work environment, relaxing the dress code, providing assurance about salary, and negotiating changes in work tasks to support him in his work, including Peter mentoring a trainee;
- Peter's clients - providing information to them, supporting their need to check communications;
- the staff team – information on Peter's illness and management direction, reallocation of tasks, and roles;
- the work environment – equipment replacement and modification, and work system changes.

Dealing with Peter and the impact of his illness has sharpened Terry's awareness of his staff's needs and his management skills. At the same time, the experience has raised some personal issues for Terry that appear confused and therefore unsupported, as well as a more intense response of one woman staff member with which he is uncertain about how to respond.

Accepting painful experience	Disclosing then meeting need
Supervisor (Leo):	
• "Work was very important to Darren. He was driven by the dollar. He had a horrible life, and was making sure his family would be financially secure. I could see he was sick. He had back pain. He was admitted to Monash and three weeks later told he had cancer."	• "We had a huge argument about his illness. He thought we were getting rid of him. I managed his back pain – he wore runners to work and then changed into his boots. It took him forty minutes to put his boots on. He did that in our office, away from others. It compromised our productivity. Fortunately the job was in a low, so I could re-jig his work. He was a proud man, but the blokes were relieved when he went on sick leave. Many of them didn't want to see him wither away."
• "Darren never came back to work. He said he would, but I was resigned to the fact he would not come back."	• "After he left, I called him every day and gave feedback to the boys. I visited him after work. When the chemo started I reduced the calls, as he withered away. I had to make him take sick leave. We had a BBQ for him and he came, but could only stay for twenty minutes. I had a "toolbox" meeting before the BBQ, and told the boys not to expect him to be well. I described how he looked. They were still shocked when Darren came in."
• "I didn't see him before Christmas. Then he died. That was shocking and I feel guilty about it (not seeing him)."	• "It has been sad for me. My wife and I have been grieving. My family has been concerned for me."

This summary of Leo's interview is sparse compared with the previous two interviews. Perhaps this reflects the more 'macho' environment of the construction industry. Leo's brief comments nevertheless reflect a deep affection for his employee (Darren), and an expression of compassion that is simple and direct.

Leo understood work's importance to Darren, and not only ensured Darren kept working as long as he was able, but also protected Darren's dignity by providing the office for a man in great pain to put on his work boots. The BBQ was another expression of the company's support for Darren. Leo's briefing of the workers before the BBQ on Darren's deteriorating condition appears to be a further attempt to protect Darren's dignity with his workmates. Yet embedded in Leo's narrative is an almost inexpressible sadness. The difficulty this workplace has dealing with the emotion surrounding Darren's illness and death may be the cause for the unresolved emotions still present for Leo at the time of the interview – guilt, and grief.

Elements for a workplace assessment framework

Each of the summaries of the three ill people's interviews also establishes some of the elements for an assessment of workplace support for a person with a life-threatening illness. From Paul's interview, these elements are:

1. **Human resource management:**
   - introducing greater flexibility to his work rosters.
   - protecting his need for privacy after surgery.

2. **Occupational health and safety:** ensuring his shift partner could work with his physical limitation with lifting.

3. **Health promoting care:**
   - providing a supportive environment for his colostomy.
   - developing a supportive response from fellow workers for feelings of depression and isolation.

From Clare's interview, these elements are:

1. **Human resource management:**
   - ensuring payment of leave entitlements.
   - flexibility with return to work rosters and rest breaks.
   - inviting the ill person to staff meetings.

2. **Occupational health and safety:** reorganising the physical environment to make filing less physically demanding.

3. **Health promoting care:** providing emotional support.

4. **Meeting production needs:** attention to inter-office communication to ensure smooth transitions with staff on other shifts.

From Tim's interview, these elements are:

1. **Human resource management:**
   - accepting the need to change some work tasks.
   - flexibility with return to work rosters and rest breaks.
   - attention to inter-office communication to ensure smooth transitions with staff on other shifts.
   - inviting the ill person to staff meetings.

2. **Occupational health and safety:**
   - support with lifting.
   - provision of a new desk to meet OHS requirements.
   - an assessment of the work environment by a therapist.

3. **Meeting production needs:**
   - support with typing.
   - modification of work equipment so Tim can continue to work.
   - renegotiating contractual obligations.
   - succession planning.

Interviews of other ill persons identified the following issues that may be incorporated into a workplace assessment protocol:

> A scientist working with dangerous goods (acid) expressed concern about carrying these items. He has less feeling in his fingers, and less control over them. As his body weakens, he is concerned he could fall over.

> A CEO in a not-for-profit community agency reported hearing loss after her treatment for a cancer. This has made it difficult to participate in meetings, and strains her concentration. She has also reported difficulty remembering things. This "has affected my confidence and judgement," she says. 'Some decisions I would have made differently.' This woman also said, "Some things don't matter as much any more. I haven't given leadership or shown strength in the last 3-4 months. I just don't care."

> A small business owner found her vision was affected after chemotherapy. She couldn't drive. Nor could she provide business counsel to her clients due to loss of concentration during an interview. Molly had no money coming into her business during and after treatment. When she missed a payment on her leased equipment during treatment, she then had bank charges added to her debt.

The summaries of the three manager/supervisor interviews also reveal some of the elements for an assessment of workplace support for a person with a life-threatening illness. From Jarrad's interview, these elements are:

1. **Human resource management:**
   - manager clarifies his level of responsibility for managing the ill person and the impact on staff work loads and roles with senior management.
   - maintaining identity of ill person as valued team member.
   - deciding not to acknowledge the seriousness of Tim's illness results in loss of Tim's experience with no succession planning.

2. **Occupational health and safety:** deciding not to acknowledge the seriousness of Tim's illness leads to emotional upheavals later on.

3. **Meeting production needs:**
   - reallocating ill person's tasks and spread work load.
   - deciding not to acknowledge the seriousness of Tim's illness results in production upheavals throughout illness and after death.

From Terry's interview, these elements are:

1. **Human resource management:**
   - manager establishing his authority to act with senior management, including payment of leave entitlements and availability of resources for staff training and support services.
   - manager establishing an understanding with the ill person on communicating the ill person's needs.
   - developing an agreed strategy with the ill person to inform selected colleagues then the whole staff team.
   - ongoing ability to negotiate changes in work roles and tasks.
   - information on management response to the ill person's situation and staff needs. Encourage open communication.

2. **Occupational health and safety:**
   - manager researching the illness with a specialist support organisation.
   - manager protecting the privacy of the ill employee both at work and home.
   - relaxing the dress code to relieve pain and stress caused by wearing a tie.
   - replacing and modifying equipment as required to support an ill person's work capacity.
   - uncertainty about responding to the emotional stress of a staff person who is very close to the ill person, and has experienced a recent bereavement.
   - manager uncertain about meeting his own needs.

3. **Health promoting care:**
   - supporting ill person and wife to learn about his illness.
   - carrying out a rehabilitation assessment of the work environment.

4. **Meeting production needs:**
   - promoting a person to the role of trainee to assist the ill person with some tasks, and to ensure an effective succession plan through the trainee's on-the-job training.
   - providing information on person's illness to clients to ensure continuity and smoothness of communication with them.

From Leo's interview, these elements are:

1. **Human resource management:**
   - maintaining boundaries of 'macho' work culture to protect the identity and dignity of the ill worker.
   - maintaining employment opportunity during illness for ill worker and fulfil sick leave entitlements.

2. **Occupational health and safety:**
   - organisation of work BBQ to allow workforce to acknowledge their sick mate.
   - briefing workers on ill man's deterioration to ameliorate their stress.

3. **Health promoting care:** work culture may suppress emotions, leading to later unresolved feelings of guilt and grief (sadness).

4. **Meeting production needs:** accepting lower productivity from the ill person due to low time in construction job.

Elements in the sequencing of support

The best practice of support will involve providing different types of support according to the needs identified by different parties from the narratives of their experience, and the resulting workplace assessment. Support needs for coping with work-related stress have been conceptualised around economic, emotional, information and appraisal support.[11] This report applies the same conceptualisation to the need for support for those at work with a life-threatening illness, as follows:

1. **Economic support.** This is instrumental behaviour that directly helps the person or organisation. It includes helping financially, helping others do their work, and taking care of them.

2. **Emotional support.** The person or organisation is provided with empathy, caring, love and trust.

3. **Information support.** This involves the provision of information to the person or organisation that helps them cope with the situation. It helps them help themselves.

4. **Appraisal support.** The person or organisation is given information or feedback to facilitate self-evaluation.

The interviews reveal one pattern of support does not fits every situation. How support is provided differs from one workplace to another according to industry, size of the company/organisation, the pressures in the production cycle, the nature and stage of the person's illness, their family circumstances, and the previous experience of all parties with illness, disability and death.

Therefore, rather than a simple 'kit' of support techniques that does not do justice to the complexity the research has found, it may be more fruitful to establish a framework that outlines the important elements of workplace policies and procedures for dealing with life-threatening illness. This approach is in keeping with an American study which "shows that how amenable the organisational and social environment are to the implementation and effectiveness of a particular coping strategy affect how often that coping strategy is chosen. … in terms of worksite social support, this study suggests that programmatic efforts to increase perceived support may result in more employee attempts to mobilise support when facing a problem"[12]

The public knowledge that support will be provided in a workplace may be a significant factor in mobilising whatever support different parties can offer. This is why it appears important to develop a workplace policy framework that ensures support is built into a business's organisational and social support environment.

This section will report on issues arising from interview participants' experience of providing different types of support or responding to different needs. Each of the issues considered may be justifiably included in a work organisation's policy and procedures framework to support those with a life-threatening illness.

Economic support: some issues

Income maintenance
Those interviewed pointed to the use by ill people of sick leave, annual leave, and long service leave separately and in combination to maintain their income as much as possible. In cases where the person's illness eventually stopped them working, maintaining their income was no longer always possible. One public sector employee had over a year's accumulated long service leave that he planned to take on half pay. Another business provided their ill employee a period of leave without pay after her entitlements were exhausted, as a means of keeping her job open for her to return to after treatment.

Dave's manager said Dave had used all his leave entitlements before Dave's illness prevented him from working. Darren's supervisor estimated his company paid Darren "possibly 100 days of sick leave". Tom was on a contract with a 25% loading for casual work, with no sick leave. His boss estimates if Tom had been on permanent part-time, "he would have used all his sick leave by now". Tom is still ill from chemotherapy, and is "below the poverty line now earning $19,000 this year."

Mary paid all her part-time ill employee's entitlements, "and an extra week to help out." The business also provided about four months unpaid leave in keeping the job open for their ill employee to return to after treatment. During this period, the employee had to reduce her spending, and fell three months behind in her rent.
In addition, Bev's illness also had considerable economic impact on Mary's business. Indeed, it threatened the stability, if not the viability, of this small business. This impact was exacerbated by the economic impact of Bev's illness and staff leaving. Mary had to pay out all the holiday pay for staff that left, and sick pay for Bev. This meant her wages bill went up 40 per cent on the previous year.

During Peter's illness, his manager was authorised by senior management to continue paying Peter while he could work.

Lewis had income protection insurance, so that when he was ill he took half sick leave and half unpaid leave, then received a personal payment from his income protection insurance.

The research shows a range of income maintenance arrangements were put in place between employers and employees, but that for some of those interviewed, these arrangements were insufficient to maintain an adequate level of income. One casual worker was living below the poverty line, and a part-time employee with two children was falling behind with her rent. The relationship between employment, life-threatening illness and income maintenance, especially its impact on family and personal well-being, is a relationship that requires further quantitative research.

Costs and benefits to the company
The real costs and benefits to the company could not be quantified in this study. The survey does show that while there are costs to business in supporting an ill person, there are also important benefits.

The costs to the business of supporting an ill person in their employment seem more readily measurable – for example, factors identified such as the cost of time lost, cost of new equipment, and the cost of reduced productivity lend themselves to quantification. However, the identified benefits to business often seem more intangible, and include maintaining the business's reputation for excellence, the transfer of knowledge and expertise to other staff, improved staff relations and more reflective attitudes to work and life.

Time and expertise lost from the organisation's business was identified as a cost to one business, as was modifying workplace equipment. Terry said the main cost to the Department in maintaining Peter's employment were modifying Peter's computer and telephone, and time away from the office for medical appointments.

Similarly, in another public sector organisation, Les estimated their business bore the cost of Tim being less able to input into a consultancy project due to his illness, and the cost of Tim's reduced time to provide consultancy advice to industry. Conversely, because the ill employee is a world authority in his field, his presence at work, and his knowledge "means the place functions much better."

In a national manufacturing organisation, the local management priority in responding to Gary's illness was to focus on succession planning. The manager, Angela, acknowledged Gary's national and international reputation in his field of research, and the importance of Gary's project for the organisation. Angela believes Gary's expertise and advice is invaluable to their business and the industry they serve. Angela has bought one day per week of another staff person's time to work with Gary, and has advertised for another person in Gary's project. Other people have been brought in to the project team. Angela says they now spend more time planning. "This is Gary's way to make sure we meet the project objectives without losing ground." Angela also hoped to have a casual contract in place for using Gary's services after Gary leaves the organisation in a few months time. The cost of these transition arrangements supports Gary while strengthening the organisation to function effectively after he leaves.

Tom's boss could not identify any costs to their business caused by Tom's illness and treatment, as he worked casual hours. The company benefited by Tom being available to work "at any time that fits in with how he is feeling."

A benefit identified by one manager was a development in staff relations. When David's workload was reduced through illness, the company increased other staff workloads to cover his work. David's manager reported the challenge to support David led to strengthening some work relationships and interactions within the work group.

The willingness of staff to forge closer work relationships may be influenced by their experience and perception of life-threatening illness. In a small business, staff were very understanding of both the ill person and the business's needs. "One has given up time from her studies, and her duties at home to help us out," Dianne says. "One who had also had a cancer was very supportive. They are a very good bunch, and empathetic. We all believe it could have been one of us."

Alternatively, when Mary took on a significant extra load as office manager when one of their staff was ill, she believed there was a significant emotional cost to her and her children due to the increased work pressure.

A public sector manager said his Department has benefited from maintaining Peter's employment during his illness because Peter is training a young staff member to do his job. The organisation also benefits from Peter's availability to consult on procedures and cases, and "the inspiration he provides to others by working with his disabilities."

Balancing productivity needs with emotional support
Each business is endeavouring to meet a range of economic, social and personal needs. At times, these needs may be in conflict, as the following experiences indicate.

Many businesses pride themselves on having a 'family atmosphere'. But Moira's experience identifies how the survival needs of her small 'family' business may be quite different at a number of points from the emotional needs of the ill person. For example, Moira's ill employee did not want the company's clients to be told of her illness. Moira noted "some clients felt uncomfortable about our employee's appearance during treatment. When her hair started falling out, she agreed we could tell all the clients. But she had told some, and we didn't know whom she had told. There were very many stilted conversations. The reaction of some clients has also caused some discomfit for staff." When the economic needs of the business were subordinated to the emotional needs of the ill person, the viability of the business itself may be at risk.

The situation is almost reversed in this next case. Three months after his diagnosis, David could no longer drive and he commenced restricted office duties. He had a palliative care volunteer who drove him to work and back home, as well as travel assistance. David's treatment meant he "was not able to handle any amount of pressure or stress. My mind hasn't been affected at all." At first, "they just told me to do as much as I can and left it up to me. They were happy with whatever I thought was acceptable. Communication was the key. I kept advising Jarrad what work I did." David worked even when he had filled in sick leave certificates, although he said he didn't get much done. The work arrangements included David assessing his level of tiredness, and "using common sense" about what work he did during a sixteen-month period when he worked three hours per day for two days per week.

At first, this seems a reasonable arrangement for balancing production and personal needs. This approach may also have reflected the fact that David worked in a regional town, and his manager was interstate. But it is a 'hands off' management style that places a great deal of responsibility and initiative for maintaining communication and monitoring the situation on the ill person. While this was welcomed at the time, David was to comment sadly later on during his extended sick leave about the lack of social relationships with his work colleagues. This may be the result of subordinating David's emotional needs to the production needs of a physically distant management.

In another workplace, the existing employment arrangements and procedures for filling an absence caused by an ill worker provide a satisfactory framework for balancing production and personal needs at this stage of Paul's illness. Paul's boss, Tom said the nature of the shift work in the industry meant Paul's illness had not affected business productivity "to any great extent. We can cover him if he is not able to work. We call in others to fill his spot."

The main impact for Tom is if he needs to replace Paul during a shift, because the replacement has to be paid for the full shift, even if they only work two hours. "It is the same issue for any worker who is ill and unable to complete a shift," Tom says.

Similarly, when Brian returned to work as a transport worker after surgery and treatment, he felt he was ready to return. He started doing split shifts in the depot where he was employed. "I managed my return to work," he said. "I rested on the couch at home during the split between shifts."

The way a business responds to a person's illness may also depend upon their occupation and status in the organisation. The report has already noted how two organisations put detailed succession plans in place for key experienced staff with a life-threatening illness. When Rosemary, as Managing Director of an industrial design company, returned to work on a half-time basis for six months after cancer treatment, she shifted some of her responsibilities to others. She said, "I needed to remain positive in case they didn't think that I could cope." However, while the organisation offered considerable flexibility for their MD to return to work after her treatment, the following interview suggests that when the person in authority is also the one who is ill, they are not in the best position to balance the organisation's needs and their own personal needs.

While Rosemary was having treatment and not around as much, a senior manager, Michael noted productivity did go down a little. He thought there was a lack of initiative and not as much new work. Michael was concerned there was a lack of leadership from Rosemary, as staff looked to her to drive the organisation. Staff brought issues to him so as not to worry Rosemary. The overall impact on Michael is that he has needed support with his stress levels, especially when Rosemary was off work. Michael acknowledged he didn't have the energy to provide the leadership the organisation needed, and that was partly due to Rosemary's illness.

Michael felt he had a number of responsibilities delegated to him without the authority to deal with them. "I didn't know when she would be here or not. I had my full role plus hers to take up. I also had to do a number of tasks I had not done before." The situation Michael describes is full of ambiguity. "When Rosemary is at work, I feel she expects staff to go to her. She doesn't want to feel left out, but there are times when she needs her own physical and emotional space. At times she gets very tired, and is not coping emotionally. Rosemary would expect of herself and others that if you are at work, then you can do your job! That is how she sees herself at work."

Looking back, Michael regrets the lack of planning from the beginning. "There was no consideration of the risks and implications for the organisation. It all kind of just happened. There was no opportunity to talk through how to manage both the organisation's and Rosemary's needs, including the threat of Rosemary's death."

Michael would have welcomed external help to know how to support Rosemary as well as support the organisation. "We didn't know what was the greatest priority, and so in most cases Rosemary was put first. Eventually three key staff left."

The ambiguity and complexity of meeting production and personal needs is heightened even more when the ill person is the business owner. Before her treatment, Molly worked fourteen-hour days, six days per week in her own business. After her cancer treatment, Molly contracted most of her work to colleagues and worked one-two days per week. Molly had several ventures in her business. Her former business partner withdrew from being Molly's administrative assistant after Molly was diagnosed with cancer. The four people Molly employed on projects have been put off as the projects were finished. "I pushed myself to the limit to complete my work commitments over a period of seven months," she said.

Molly managed this situation "by being truthful and open. I was up front with people about what was happening and why. I was honest. This was really important." When Molly was low on energy while running a training workshop, she would have a break and a colleague would step in to take over for a time, until Molly was ready to take over once more.

There were some clients Molly has not heard from since they knew she was ill. "Now I am not sure how I will contact them to renew my business," she says. "It is a huge challenge for me to face that. Will I be dealing with their fear of cancer, and then my fear of their projection?"

When business needs submerge personal support options
There are significant economic pressures on business that seem to contribute to business production needs submerging the needs of an employee with a life-threatening illness. The research demonstrates how these pressures can further undermine the health of the ill person.

In one organisation with a recent history of restructuring and redundancy the personal needs of staff, manager, and the ill person seemed to disappear into the background as the organisation focused on its own survival. An interview with the ill person's manager revealed an organisation dominated by the senior management agenda to meet deadlines, keep to budget, and maintain the quality of its research product. The local manager's strategy for responding to Tim's illness could be described as an attempt to quarantine Tim's illness from the intervention of the corporate managers of the business.

At the level of local management, the response is compassionate but limited by the lack of corporate commitment to support for people with a life-threatening illness. The manager laments, "I wish we did have policies and procedures in place. Tim has worked here for thirty years." Tim is also aware of the risk to his future employment by being open about his illness. While Tim plans to leave, he has set some goals he wishes to meet. He has discussed them with his manager, but is unsure of the views

of senior management. Tim said, "So I told them I had health problems, not a terminal illness. They would treat me like a lame duck from then on."

This organisation's narrow business focus hides the potential risk that if Tim's illness affects his work performance or occupational health and safety, it will not be acknowledged in time to prevent mistakes in the production process or a work accident.

Angela says their public sector organisation is "now driven by industry", and upper levels of management question Tim's position because it is not fully funded by contracted work. This causes a dilemma for Angela and Tim in dealing with the personal dimension of Tim's situation.

Angela recognises Tim's needs to work shorter hours to rest, and to spend time with his family, which as far as senior management is concerned "is unheard of. It would be nice to know if the institute cares if someone is sick at work." Tim seems aware the organisation's attitude causes difficulty for Angela, so when Tim is at work, Angela says "he works non-stop, longer hours than me." Arrangements for increased work flexibility may need to be accompanied by a commitment to the ill person's job security. U.S research findings established that "when supervisors reassured them (carers) that their jobs would be secure, they felt relieved and grateful as a result."[13]

Lewis's illness occurred at a peak productivity time for his organisation. He was supported to leave for treatment immediately after diagnosis, and this removed the stresses of work from his life. As CEO, Lewis has found since returning to work after successful treatment that he was not able to remove the stresses of work as he has done in the past. In fact, this time is the most stressful of the entire experience. Now Lewis believes it would have been better if "the Board or my Doctor had insisted I go away and not come back until I was ready. It would have been better to have a complete break."

The pressure of business on an ill person may be even greater when the ill person is the business owner. Barb found marketing her business very difficult as her treatment for cancer progressed. She said her confidence was low for this work "when I lost my hair and was bald. A lot of people don't like dealing with sick people. My business was falling apart." Barb arranged for her treatment to be early in the morning so she could then come to work. After her treatment, Barb was not in remission, and had been already told a number of times she had two or three months to live. She says, "Working hard has been detrimental to my health. I haven't listened to my doctors or to my body in the last twelve to eighteen months. My body couldn't recuperate from treatment. There was too much stress on me trying to keep my business going."

Molly leased her car, telephone and computer for her business. She was then locked into contracts for each of them as none could be varied once she was diagnosed with cancer. This was a huge liability for her business. "I haven't been interested in money or able to think about it. I haven't been paid by the business for over twelve months. Fortunately, I had income protection insurance."

A safe and healthy work environment
Productive capacity in business is maintained or enhanced by sustaining a safe and healthy work environment. So Luke was pleased when Sean, his supervisor at a Melbourne engineering company organised an occupational therapist to assess the workplace, and all the OT's recommendations implemented.

Luke was also aware Sean had spoken to their clients about his illness. "They have been understanding and helpful," says Luke, "and they have cut me some slack and not been as demanding."

Luke says his doctor is keen for him to keep working as long as he is able. At this time, Luke is not sure if there is a point at which he would cease work. He has "asked Sean to tell me if my work is no good. Then I would think about finishing." But Luke is not sure if Sean would tell him to leave work. "I think he would leave it to me. Or he may tell the wife its time." Then Luke said, "Sean would call a spade a spade, and sit me down and ask how I am going."

Luke's reflection illustrates the potential ambiguity in two principles of workplace occupational health and safety. The first principle emphasises the employer's responsibility for providing a safe and healthy workplace. The second principle stresses the importance of employee participation in workplace safety. So while it is important that Sean listens to how Luke is coping with his illness at work, and responds to Luke's needs for safety at work as management is able, it is not appropriate for Sean to forgo his management responsibility for safety at work because his staff member has a life-threatening illness.

Barry says his colleague James "comes to see me to talk about how his illness is affecting our work. He knows that everything stays with me. We've had three or four discussions like this." Barry helped make his mate James's work safe, but was concerned James "would be stuck at a computer. He is a hands-on practicing scientist doing laboratory work." Even as a workmate, Barry has a greater over-riding responsibility for workplace health and safety than he does for his colleague's feelings.

Tom is vulnerable to the same dilemma, expecting his employee Paul to tell him if he wasn't coping with his workload. In seeking to address this situation, Tom believes it would be helpful for Paul to have someone in the company he can talk with in confidence, so he does not feel isolated. This contact person could also inform management if there are issues affecting Paul that need to be addressed. Over-tiredness is also something Tom says he needs to look for in Paul's performance.

As well as the specific organisational challenges of sustaining a safe and healthy work environment while employing a person with a life-threatening illness, there are a number of specific issues that arise. The discussion in this section has identified issues associated with equipment hazards, tiredness, and loss of concentration. Other issues identified by this study include loss of strength, lifting hazards, depression, dizziness, impaired vision, and over work and associated stress.

Peter's illness makes him tired, "especially by the end of the week." He has lost strength in his legs and arms. He says, "I could fall over and break a bone. I can't lift things." The disease has also affected his voice. This has been embarrassing for him, especially when dealing with the public. It has also been hard to communicate with work colleagues. While Peter says he tries to be upbeat at work, "I have days when I feel depressed."

Barb has many needs caused by her illness and treatment that have not been met. Initially she experienced tiredness and poor concentration. Her eyesight was affected, and she had bad depression and mood swings. Barb said she had been driving and hit by dizziness. "I was more likely to do things that were dangerous when my staff were not around. There were things that just had to be done."

Toni had taken on more responsibilities since her boss was ill. Both staff in Barb's small business have increased workloads since Barb's illness progressed. Recently Toni decided to take some time off, and now doesn't stress as much. Yet the uncertainty about her future 'was a big issue' for her. If Barb died, "we didn't want the franchiser to come in and take the business over. We didn't know if they had a right to do that. What do you do? We didn't know whether we should still come in to work and try to keep the business going. You need to know what has been planned."

Emotional support: some issues

Life-threatening illness and death: a range of tough emotions
The presence of life-threatening illness and death evoke a range of emotions that many people find are tough to deal with. This was equally true for those interviewed in this research. Faced by such emotion, many of those interviewed felt unsure of how to respond. Their ambivalence led to miscommunication, conflict, avoidance of work issues, and inaction.

When her boss told Toni that she had cancer, Toni's first response was shock. She thought, "O no, not someone else!" In recent years, Toni had three people close to her who had died of cancer. The news was very hard for Toni and the other staff. "We didn't know what was happening. We didn't want to ring her if she didn't come in to work. For a long time, we were just holding our breath. If she didn't come in, I didn't know if she had died. So I made a pact to ring her each morning, or she would ring in. Some things didn't get done, because we didn't know about them. Some things I didn't like to do, in case I got it wrong. I have been learning the business. Some tension built up and we had a blue."

Angela observed others in their workplace experienced grief and sadness at Tim's illness. Angela also wonders what she will do when Tim leaves. She says she sometimes feels "really guilty asking Tim to do things." She also believes she is "more aware of her responsibilities as a manager to find a way to support staff."

Wendy was the accountant/office manager. Darren told her he had cancer. Wendy felt helpless and sad at this news. She worried about whether offering care to Darren would be seen as interference. "I felt totally inadequate. Darren's cancer seemed so unjust. He was not well-educated or very resourceful to deal with it. His biggest concern was running out of money."

Supporting staff to understand and respond empathetically to their own emotional reactions to the reality of a work colleague with a life-threatening illness is important to ensuring the ongoing effectiveness of a work organisation.

Burying emotions at work during a life-threatening illness
One response to the tough emotions evoked by life-threatening illness and death is to push them away. When David rang the executive manager to say how serious things were, the executive manager told David not to worry about work. "He said – you worry about getting better, and we'll worry about work." David greatly appreciated this being said.

However, when David was interviewed he had been on sick leave for eighteen months and was missing work. In particular, he expressed his loss of the social relationships he enjoyed at work. He still experienced a sense of belonging at work. "They still want me there. There is a – we can't wait until you come back – sort of thing." At the same time, David "hadn't heard from his manager for months. Nor have I seen my co-workers. They haven't been very sensitive about it at all really. I look different now. I grew a beard to disguise the bumps. They looked a bit nasty. They don't know what to say because of what I look like."

The culture of many workplaces may encourage workers to hide their feelings. In the U.K., Charles-Edwards observed that "some people view human functioning in 'split ways' that see emotion and thought as virtually in opposition to each other, rather than regarding our feelings as part of our intelligence that provides us with valuable information and energy."[14] Wendy, a bookkeeper in a construction company, suggested this attitude to emotions was a traditional masculine attitude that was strong in the predominantly male environment of the construction industry. She observed the project managers in the company had difficulty coping with Darren's illness while he was at work, not knowing what to say. They would say, "I would get upset if I spoke to him about how he was getting on." Wendy said, "You don't get upset here, especially not men! The men switch off. They don't deal with it. They think it eventually goes away. Darren's foreman never went to see him in the five months Darren was on sick leave. He was frightened of breaking down."

One ill person in a public sector organisation identified another cultural dimension in their workplace, where emotions were segregated and compartmentalised from work activity. Emotion was repressed at his work in favour of busy activity, which was highly valued as progress. He said his workplace "was busy, motivated, selfish and they are just getting on with their own lives."

The influence of this cultural attitude to excluding emotion from working life even affected staff working in the health industry that are familiar with patients with life-threatening illness, according to one employer. "They don't know what to say or do when it's a workmate who is ill. They need direction on how to deal with their anxieties. Staff training may be needed to help them manage working with Paul. There is an air of depression for some who know him well. Some staff accommodate his illness by treating him as if he were a patient." However, not all staff were limited by this cultural attitude to illness and the emotions life-threatening illness evokes. According to Paul's co-worker, it is the "staff who work with Paul who are very aware of his situation. The company rosters him with people who are aware of his needs."

Another factor that may cause people to push away the tough emotions evoked by a life-threatening illness is a person's previous experience with death and grief. A U.K. researcher noted that "it can be uncomfortable being near another person's grief, and … it may be a reminder of past grief (losses) or our human vulnerability or our mortality."[15] In her interview, Wendy shed tears as she recalled that her son committed suicide when he was sixteen years old. "People crossed the road when they saw me coming," she cried. "I lost friends." For Wendy, dealing with the issues around Darren's dying, death and subsequent grieving has been exhausting. At times during his illness, Wendy would go home early if she felt overwhelmed. She feels less patient now with the 'trivial matters' in her work, and feels alone at work. Her main support is at home, from her partner. Wendy says, "I would like someone to talk to. Self care is important. In this situation, there is a need to be resourced by someone." She feels her work has become harder "because you become helpless – you can't do anything to help." The importance of having a person who can debrief the tough emotions evoked by life-threatening illness is reinforced by a study that suggests a support strategy for managers may be to help them articulate their own needs through sharing their sometimes confusing feelings.[16]

While many people say the barriers they put up to protect themselves from the emotional pain and vulnerability evoked by a life-threatening illness are for the benefit of the ill person, the ill person may feel more pain by their experience of being shut out. A small business owner with cancer said it was unhelpful when her staff "tried too hard not to upset me. It made me feel that I wasn't in control." After she had talked with them about this, "they treated me the same as they had before my illness. I was accepted. They put up with my mood swings, even if they didn't understand them."

Similarly, Gail, the production manager in an agricultural business, has felt guilty for downplaying the reality of the situation caused by her boss's illness. She did this "to protect staff morale, to protect her boss, and to protect the organisation." Now Gail acknowledges it would have been helpful to have had external help to understand what her boss was going through, what to expect and how to be better prepared. Gail became exasperated with her boss at times. "I wanted to tell him that we could cope, and he should come back when he was healed and ready." The lack of support for her needs led Gail to feel resentment towards her situation, and increased her stress.

As the production manager, Gail realised later that she needed more support herself while her Managing Director was ill, "as I thought of others and not myself. There were times I went home in tears, which had to do with all this, and I would take it out on the family and kids."

Dealing with the emotions evoked in the workplace by a life-threatening illness is at the heart of the conflict between the positive valuing of work in Australian culture, and the negative valuing of illness. This work culture functions by diminishing the humanity of the ill person through social isolation and stigmatising, segregating, compartmentalising and demeaning 'unproductive' emotions from 'productive' activity, isolating previous life experience of death and grief from present realities, and justifying this as being in the best interests of the ill person.

Because the prevailing work culture is largely taken for granted, the onset of a life-threatening illness to an esteemed and valued work colleague is an unsettling intrusion to accepted patterns of working life. The only answer the culture has for this intrusion is to push it away, but the personal nature of the work relationships disclosed in this research suggest this strategy is neither simple to implement nor desired. The competing realities may cause a sense of crisis and confusion for employers and managers facing this situation, perhaps for the first time. Yet when this confusion can be accepted in a safe, non-judgmental environment, the business may begin to grow towards a more balanced and enlivened work culture.

Sharing emotions at work
The barriers created to compartmentalise emotions from productive activity may be lowered as trusting relationships and a sense of safety develop between the ill person and others. A Melbourne report into trauma and grief at work suggested that "effective workplace support involves creating an atmosphere of emotional safety … empathetic and active listening through clarifying, containing, being genuine, ethical and respectful of difference contributes to this sense of safety."[17] While it may need the support of a facilitator to guide this process, some of those interviewed have contributed to emotionally safe environments in their workplace.

One ill person reported the encouragement he receives from a colleague who had prostate cancer in the past year. Lewis also said another staff member with breast cancer gave him strength. Now fully back at work, Lewis says he has a "deeper understanding of things. I provided telephone support to a colleague who had cancer. I go out of my way more to talk to other sufferers or write to them."

Barry has found it humbling that his mate James has "come to me for advice and support. This has had a big impact on me. The situation might get to the stage where I am completely out of my depth. I would cry a lot that I can't help somebody that I would like to help." Barry has also valued that his and James's manager talked with him about what he planned to do to support James. Barry was pleased the organisation valued James's contribution so highly they would make a significant effort to help James.

Toni says that she and her workmate have got closer since their boss became ill. "We talk about the situation between ourselves, so we know what is happening. We let off steam a lot. There were times we thought Barb was not being fair. She would forget things she had told us, and then be angry with us. We decided to take it on the chin, and give support to each other. Sometimes it has been very hard. If I hadn't known her for such a long time, I wouldn't still be here."

Becoming emotionally detached from work
A scientist of thirty-two years said "my work is a very important part of my life. I grew up with a protestant work ethic. It is really interesting, rewarding, exciting. But I am leaving at the end of the year. I have had enough of work. I am less emotionally devoted to the place. I feel free to take off to do family things. It is time to do some other things and there is financial provision for that. But I may sack myself before then!"

Employer/supervisor advocacy

One employer found Centrelink unhelpful in the business's endeavours to support their employee. One Centrelink reporting day, their employee was rushed to hospital after an allergic reaction to her treatment. Because she couldn't report to Centrelink, the ill employee would not have received her pension. Her employer found Centrelink extremely frustrating to deal with in trying to sort out their worker's pension payment. "Their form didn't even have a response for not reporting – 'have you been ill?' he said."

Barry says James's manager will take things up to support or protect James within their company without James knowing about it. These forms of advocacy may typify the important role of advocacy by the employer/manager in supporting an ill person in their workplace.[18]

Information support: some issues

Kellehear emphasises the delivery of health promoting palliative care depends on "the importance of education and information in the achievement of health goals".[19] This may include information and education about the nature of the ill person's diagnosis and possible illness trajectory. Disease and illness do not stand in a one-to-one relation. When a person is given a diagnosis of disease for their sickness, the illness process may have already begun with the person's prior awareness of changes in body feeling. Peter had talked with his good friend and manager about tests he was having for symptoms that concerned him.

The course the disease follows is likely to be distinct from the trajectory the illness follows, because "the illness experience is an intimate part of social systems of meaning and rules for behaviour . . . . how we perceive, experience, and cope with disease is based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meaning we employ."[20] When a sick person tells people at work of their diagnosis, it may also confirm changes those at work had observed in the person's behaviour.

Who the sick person tells at work of their disease diagnosis, and how and when work colleagues are told are decisions influenced by:
- the workplace's beliefs,
- what the ill person believes are the 'approved' ways of being ill, and
- how the ill person perceives he/she will experience the public knowledge of such personal information they have disclosed about themselves.

These factors will also influence the manner in which the ill person presents their symptoms at work, whom they seek support from at work, and how long they remain at work. There is a dynamic interplay between biological, psychological, and sociocultural levels of sickness that ensure there is a wide variation in how disorders are defined, coped with, and responded to by both the ill person and their workplace.

The complexity of a life-threatening illness means providing the best practice of support for an ill person will change as the disease and treatment process unfolds, and the meaning of each unfolding stage also changes. The best practice of support will also change as the understanding those in the workplace have of illness, dying, death

and grief changes in the light of their past and present experience and understanding of these realities. The interaction of these medical, cultural, social and personal factors means support is specific to each situation.

While there is no master plan for best practice support for these ill people at their work, the narratives they contributed to this research reveal the meaning they found in their experiences. Within the complex array of changing shades of meaning they report, there are moments of consensus, paradox and ambiguity that are suggestive of occasional signposts indicating the way ahead.

Informing work of a life-threatening illness
The personal experience of sickness becomes a public state of illness when a person with a life-threatening disease conveys this information to a work colleague.

Several interviews reveal the importance for an ill person to have control over the information flow about their illness. Because a life-threatening illness may rob sick people of their identity as autonomous and independent selves, ensuring they retain a measure of control over the disclosure of information about their illness may be empowering and affirming of their identity. When Kathy told her manager of her diagnosis, Kathy asked him to keep the information confidential. "I would tell people as they needed to know', she said. Kathy has been pleased that she has told other people at work, 'they have been understanding and have helped me change my way of work. They have also worked in with me on succession planning."

Barry's work colleague Tim told him about two years ago he had motor neurone disease. Barry said, "I didn't think of it in a terminal sense. It is the first time for me." Barry said Tim told him the news of his diagnosis when an ergonomic assessment was being made of Tim's desk. The desk was causing problems for Tim at work, especially with pain in the legs. Tim told the women in his work area about six months ago. "It didn't go down well with one of the girls," Barry said. "Because Tim is a pretty private person, we haven't broadcast anything. Those who know are dealing with it." Barry agrees keeping Tim's illness confidential is best because "at this stage Tim is still dealing OK with his illness. That is not hiding it. It's just giving Tim dignity."

Managers have a key role in deciding on a strategy for informing others in the workplace. In one business, a manager respected the ill person's wish to tell colleagues individually, while another manager linked the disclosure of information to the need to rearrange workloads and work roles.

When a lump was diagnosed, David told a co-worker the news "out of courtesy" and Jarrad, his manager, "to arrange time off. I was oblivious to how serious it was. Jarrad later informed every-one of my circumstances by email. He explained I couldn't work as I used to. My work was passed on to someone else."

Another manager used the disclosure of information to staff as an opportunity to provide them with information and education about the person's illness. A public sector manager, Sean organised an information session for staff on Luke's illness. Luke said the staff "were initially taken aback, and then they rallied around. My work relationships have strengthened since then. Their understanding about my disease helps. Sean explained what I would be going through and what would confront them." Luke finds other staff are willing to help him. He says "it makes my work easier and more fruitful." Luke also says he is more understanding of his work colleagues. "I respect them more, and I am no longer just looking out for my self." Luke is pleased to be training a junior staff member to do his job. "This is a new responsibility I have taken on, and I enjoy helping her to know the job. Also, the trainee takes a hell of a lot off me." This experience is consistent with Platt and Gifford's finding that potentially discriminatory behaviour towards ill people is brought about not so much by ill-intent, but rather ignorance about the particular illness.[21]

One man had to begin treatment three day after he was diagnosed. As a CEO, he told his Board chairperson as soon as possible "There are always rumours in the absence of true data," he said, "and I wanted the news to come from me." The response to this direct communication he described "as incredibly rewarding and humbling. It strengthened my relationships with those I work with."

But not all disclosure of information about a life-threatening illness goes so smoothly. Gail was a production manager who found out the Managing Director had cancer from the MD's personal assistant. Gail had been on an inter-state trip and the MD has emailed her to phone him back. When Gail rang back the Managing Director's PA told her the boss had cancer. Gail said, "I was extremely shocked, and a little frightened to be honest. It was quite traumatic." Gail's traumatic experience at being told in what seems an unsafe manner for her appears to have coloured her whole experience of working through the period of the MD's illness and return to work. Some time after the MD returned to work, Gail left her employment in that organisation.

Jude's first response to news of Tanya's illness was disbelief, then concern for how his small computer services business would cope. Another information technology worker had resigned a week earlier, and the confusion about what would happen to Tanya caused uncertainty for Jude. Tanya didn't want new staff that needed to be employed to know of her cancer, and once Jude acceded to that, he found he couldn't be clear with prospective applicants about times and shifts they were expected to work. "We employed one person who resigned after one day," Jude said. "A second person refused the job because he couldn't work the extra hours we needed at the time. It took a month of interviews before the fourth person we offered the job to, took it. We lost clients due to appointing the wrong person." In endeavouring to support their ill employee, the employer *de facto* allowed their ill employee to define and limit their management role and responsibilities as an employer.

These experiences of informing staff about a work colleague's illness invite the following best practice possibilities:

> there is value in negotiating with the ill person about a strategy for managing the disclosure of their personal information about being ill. In particular, this strategy can empower and support the ill person in their work identity.

> a planned information strategy can provide information on the person's diagnosis, information about the illness, details about staffing issues (from work-loads and role changes, to succession planning), and support strategies that will be available for all employees.

> an information strategy may benefit from the recognition that some people may miss out on the planned release of information, or be traumatised by the way they hear the information, and need other supportive processes put in place to de-brief their experience.

> it is inappropriate for the ill person to have control of the information strategy, even (and perhaps especially) if they are the CEO. This is to ensure the needs of the ill person and the work organisation are both respected, and where they differ, that a process of negotiation is put in place to resolve these differences.

A U.K. report also highlights that "people who had been informed of the impact of different treatments on their work by their doctor were twice as likely to feel comfortable talking about their cancer at work."[22]

Keeping staff and clients informed
An information strategy needs to have a means of updating staff on the changing circumstances of the ill person, and how to address emerging issues. After Paul had surgery, his employer had to write to all staff and ask them not to visit Paul in hospital for several days.

In the absence of a management information strategy, the ill person may face unrealistic expectations that they deal with all the information needs of work colleagues about their illness. A workmate said he didn't really know enough about his friend's motor neurone disease. "I would hope Tim could explain it more. He is being frank. But I am more worried about him hurting himself than him compromising the organisation."

An information strategy may also assist the business to deal with its clients. One approach to informing clients is being honest about any difficulties the clients may encounter due to the person's illness. When the boss of a small franchise had cancer, the staff didn't know how to do the accounts. "We had customers harassing us. So we had to tell them about Barb's illness, but we didn't want to tell them. Some customers then told us things about the business we had no right to know, and Barb was upset about that also. Barb never told us off for telling the customers." When staff are unsure of their permission to tell clients about problems within their organisation caused by a person's illness, the staff's anxiety and defensiveness may intrude into their dealings with clients with unproductive results.

Unfortunately, honest disclosure of information about a life-threatening illness does not produce a guaranteed outcome of support and understanding for the person disclosing their illness. Many people are fearful of being close to experiences of illness and dying, including those in positions of power, and may 'blame the victim' when they are informed of a life-threatening illness. This dynamic reinforces the need for information strategies to develop processes to deal with distancing responses.

When Barb told her franchiser of her illness, "it scared the hell out of them," Barb said. "They probably wanted to get rid of me in the first place. They have come back at me because the business hasn't grown. Part of my contract is to meet certain growth targets. It's about money! There has been no leniency from them, and I am sick of fighting with them. No-one from their head office has sat down with me. Instead, head office sent a nasty letter about our performance and criticism of my staff. I was devastated. My relationship with them has been detrimental to my mental and emotional health. They are scared of the illness. The number of people who have dropped off contact because they are scared of the illness has really rocked me."

There may be a need for palliative care services to provide consultancy advice to business, especially small businesses with limited access to human resource management advice, on how to manage the complex needs of personal and business relationships affected by a life-threatening illness.

Management training and advice
A number of employers/managers expressed their ambivalence or anxiety about what to do due to their lack of information on dealing with the situation of their staff member's illness. One employer expressed his concern about how to manage with his staff if his worker's illness deteriorates. The employer saw the need for more management training for himself in managing this situation.

Another employer was angry with his employee's father, brother and sister because they gave almost no support from the time of the ill employee's diagnosis. He felt he was "dragged into the employee's illness and to being her carer. I remember driving her to hospital for surgery and being very upset, after seeing her two girls crying in the morning when I picked her up. It was one of the hardest days of my life. I visited her in hospital and fed her because her arm was too sore." The employer was advised by a Human Resource consultant in his workplace to "step back. I was too close to her. I couldn't survive continuing like that. This was a very hard transition. I have been distressed more than once." The HR consultant's helpful advice was a valuable step in the employer clarifying his role and responsibilities, and being able to put in place management processes for the longer-term benefit of all employees, including the one who had been ill.

Michael thought of providing staff training to assist them deal with the impact of Rosemary's illness and treatment, "but I felt it might have made matters worse. It may have blown up issues in people's minds and made it more negative than positive."

Fear about making matters worse for their ill colleague and other staff may paralyse a manager's desire to act, leading to the feared outcome occurring with even worse impact due to the lack of preparation and the unspoken climate of fear pervading the workplace. Employers may be encouraged to better manage their fears by the availability of protocols that provide accessible information on how to address a range of likely human resource management issues. Access to trusted sources of management advice on such protocols would be a key to ensuring the fears and anxiety of employers and managers are overcome.

Appraisal support: some issues

Lipowski suggests that how people understand the changing landscape of illness may be attributed to one of four psychosocial meanings: threat, loss, no significance, and gain.[23]

Illness with no significance for work
In Brian's view, his illness is his problem alone, "so I attend the treatment services I need in my own time." Here, the ill person has minimised the importance of his illness as if it had no importance to his work at all. Brian used his five weeks annual leave and had two weeks sick leave while recovering from surgery and treatment. Because sick leave doesn't accrue in his job, the manager gave Brian the further two weeks leave that were needed for his recovery. Brian had worked for this boss for fifteen years "without a day's sick leave. I have always helped out the company. Now they have been loyal to me when I needed it." Brian says that he is not getting any special treatment at work, "which I don't want. They expect the same job, and I expect the same treatment as before."

Yet even as Brian diminished the significance of his illness for his work, there was implicit recognition of the deep exchange of loyalty between himself and his boss. In some work cultures, the appraisal of loyalty and respect in work relationships may be muted beneath the more important appraisal that business is as usual!

Work as defence against illness's threat to the independent autonomous self
The belief that work provides a powerful source of people's identity by developing their independence and self-reliance seems to encourage some ill people to continue to work. After the initial diagnosis of his condition, Peter didn't want to work. "But as I came to terms with the diagnosis, I wanted to get on with my work." At this time, work is very important to him because it provides a sense of identity and purpose for living. He says "it gives me satisfaction when a project is finalised. I would be buggered without it in my present condition. I would vegetate without work – it gives me a great sense of purpose."

Paul's employer thought Paul had a similar attitude to work. "Paul loves the sort of work he does. It keeps him going." Paul's co-worker, Sally agreed. "Work helps Paul to function. It maintains his self-worth, and gives him necessary finances." Similarly, Michael believes his MD felt she could work through her time of treatment for cancer. "She needed to be here for her own identity and mental recovery."

Work also helped Clare to function, because it gave her a sense of financial independence. At the time of Clare's diagnosis her employer knew how important work was for Clare to have a job to come back to after treatment, so he conveyed to Clare that her job would be kept open for her. He said, "She is a good loyal worker. I think this was the most helpful thing we did for her."

Darren's co-worker agreed that work had the same, if not greater importance for Darren. He said, "Work was Darren's life, his whole identity. He talked to me about having to decide whether to have more chemotherapy or not if it would prolong his life. We never spoke about the fact that he was going to die. Even then in his mind he was going to get better and come back to work." For Darren, work was a defence against the fear of dying.

Barb said work was her reason for getting out of bed in the morning. She was the owner of her small business. Barb said, "I would discharge myself from hospital to go to work to meet deadlines. It kept me focussed and over-rode my pain." For Barb and others, work functioned as a bulwark against the threat to their identity of their illness.

These appraisals are vital to sustaining those with a life-threatening illness in their sense of identity and purpose, even when the underlying reality of the person's illness threatens this construction of their identity. However, it is important to be aware of the changing patterns in appraising the meaning of a person's life-threatening illness. The threat to life may turn to loss, and a new appraisal is required of the person that is larger than their work identity.

Other people may also experience a person's illness as a threat to their own identity. One colleague didn't have any contact with Molly for a time during her illness. When Molly was in remission after her first chemotherapy treatment, the colleague told her, "I was scared you were going to die, and so I kept my distance."

Illness as loss
Illness may also mean loss of identity, relationships and meaning. An ill person felt diminished at work when one of his bosses said, "don't tell people about your illness."

When an illness shifts from threat to loss, the meaning of the situation may become increasingly ambiguous and confusing to all parties. While the ill person is working (comparatively) effectively, the appraisal of the situation is able to focus on the objective results of the person's continued productivity and self-control. When Michael's MD wasn't coping during recovery from treatment, she rang him to delegate him some of her roles. Michael felt nothing was made specific about his new roles. "I felt I couldn't say 'no' to this request. But in hindsight she should have stopped work at the time of her diagnosis. I never really understood where I stood. There was no hand-over as she was too ill. I wished she'd just gone away and let me do the job." Michael has not been able to speak to his MD about this. He was overwhelmed with his new work roles, the anxiety amongst staff, and his own emotions.

As Molly observed, the loss of her work identity and previously defined work roles produces feelings of grief. During her illness and treatment, Molly found the medical system saw her almost exclusively in terms of her diagnosis. There was almost no support for her identity as a business owner within the medical system, and this undermined her ability to cope with her illness. "Neither my specialist nor the hospital knew what sort of work I did. They didn't ask. No-one asked me what I did!"

Molly noted the medical system lacked information about grief and loss from the time of her diagnosis. "Once you are diagnosed, you lose control of your life. You are told what you need to do. The only control you have in your life is your work/business, and so you won't let go of that, *even though you may need to* (italics added). I am grieving for the loss of that life." Molly has described how a person with a life-threatening illness may be stigmatised by the very system that seeks to help her because it fails to acknowledge her work role. She is stigmatised as "elements of labelling, stereotyping, separation, status loss and discrimination co-occur" and her relative powerlessness cannot prevent these elements unfolding.[24]

Wendy observed a similar process in her workplace. Her ill workmate, a construction worker, feared asking questions about his illness because he was a simple man. "Sometimes they don't understand the answer, and they think people are laughing at them. They fear feeling inadequate, and not being able to cope. When the palliative care nurse visited the site, she had an accent and Darren couldn't understand her. Darren made racist comments about her." Darren appears to have sought to deflect the stigma he felt because of his illness by stigmatising the palliative care nurse – the person whose presence at work intensified his experience as an ill person.

In both Molly and Darren's experience, the medical system's focus on its diagnosis and treatment of the person's sickness appears to stigmatise the social experience of the person at work, devaluing them as individuals, and "reducing the humanising benefits of free and unfettered social intercourse".[25] A more industry-focussed palliative care service may well provide the mechanism for bridging this divide, and ensuring the best practice support for the sick person.

The loss associated with a life-threatening illness moves beyond ambiguity to greater clarity when the ill person is not able to return to work. David said he was "sick of himself sometimes. I have feelings of helplessness. I go from one problem to the next, chasing doctor's appointments and worrying about what is happening to me."

Barry says it will be a shame when his mate Tim has to stop work to manage his illness. "I would like to help him organisationally if he wants to stay on," says Barry. "Like helping with transport. Or carry out an office assessment to see if there are other aids that can help him if he wanted to prolong his working life. I know he is changing his computer to a voice-over system."

The loss associated with a life-threatening illness may also be experienced by the employer/manager. One employer described how many of their own needs were neglected. "My weight has gone up because I eat more. This was a terrible time. I was here by myself. I began a time of soul-searching. It was especially difficult not being able to tell anyone Anna had cancer." There have been times when the employer "could not talk about this. At one point I wanted to close the business. It was very stressful. It also had an impact on our youngest daughter. I just wasn't available to her, because I was spending so much time at the office. The experience has been very emotional, and the work pressure is far more than I wanted. My mother has been my main support. It needed to be someone outside my work environment."

This employer's experience reveals how vulnerable many small businesses are when they endeavour to support a staff person with a life-threatening illness. When the employer suffers 'burn out' from the experience of offering support to an ill staff member, the viability of the business and its employment of other staff may be put at risk.

While the employer was eventually able to access business support through the industry HR division, their needs for emotional support had to be met from within the family network. Fortunately, her mother could meet many of those needs. What this reveals, however, is the lack of integration of business and personal support for a small business. This is a fundamental fragmentation that a best practice model of support needs to overcome.

When the experience of loss is hidden from staff, proper planning for the business becomes difficult. Toni said her boss wouldn't ask for help. "We couldn't do things if we didn't know!" The illness of the employer is very difficult for employees. Toni says "you need to know the business has been taken care of. You can't afford to shut for two weeks, because you lose the trust of your customers."

A similar story emerged in a larger agricultural business where the CEO had been ill. Gail's boss has returned to work after treatment, but was not as well as prior to his diagnosis. She says "he has reduced energy, less mental concentration in thinking big picture. Seeing a way through issues takes him longer. He would say there are more important things in life." Gail believes her boss is not at his previous peak, so other staff are picking up the slack, and some now feel resentful of this. "I have noticed it with Kylie. It increases her stress."

The failure to accept the losses associated with different stages of a life-threatening illness emerges as a critical factor in determining the level of support experienced across a work organisation for all those impacted by a life-threatening illness.

Life-threatening illness as a gain
Many of those interviewed identified gains they had received from their experience of a life-threatening illness. These gains include:
- strengthening the balance between work and the rest of life.
- a re-evaluation of the importance of one's family.
- a change in life priorities, and a new outlook on life.
- a deeper understanding of the sacredness of life, and empathy for the suffering of others.
- an experience of inner peace.
- a deepening of relationships.
- restoring a previously broken relationship.
- clarification of work roles and responsibilities.
- a family member changing their work priorities.
- discovering personal strengths.

For Lewis, work was a source of stimulation, of rewarding relationships, and income to provide for his family and the future. Since his cancer treatment finished, Lewis believes he has strengthened the right balance between work and the rest of his life. While he is back at work and fully recovered from his cancer treatment, Lewis says he has thought in recent times of resigning.

Over the time David was unable to work, the importance of David's family to him had increased, and he "would rather be at home with the family than at work."

Molly doubts she can ever take up her small business again because she now suffers memory loss as a side effect of her treatment.

However, Molly said, "I feel I am a different person now. My priorities have changed. The type of work I will do in the future needs to change also. I have grieved for my business, which I needed to do, but I don't want to walk away from it."

Now Molly has set up work from home, and created a sacred space there - a home for the soul that nourishes her, and which has put her in touch with what is really significant for her. "I have more understanding of others, and their suffering. I now believe life is about me going out and helping other people with similar things to face."

Brian says that since he returned to work after surgery and treatment for bowel cancer, "I am calmer. I don't get as stressed, and let things ride more. I am more relaxed about things."

Barb says her business is no longer the most important thing in her life. She says, "I now have a second chance at life. I have a different outlook on life and this is very important. I am looking to sell my business, have a holiday, and start a university course."

Angela observed that Tim's illness had "strengthened relationships between us because you worry and care more." Angela believes she has become more attentive to Tim's daily needs. "We have lunch together nearly every day." Others are more attentive to Tim also. Angela says, "There are plenty of volunteers if he needs help in the laboratory."

One participant observed that as a result of her illness and treatment, "My ex-husband got in touch, sent flowers, and we now talk."

Anna's illness raised a number of management issues for her employer, including:

> When Anna returned to work after treatment, she made mistakes in her work that she didn't make previously. The new staff member found that "uncomfortable when she found mistakes in Anna's work." Anna's manager then needed to take on more work herself to rectify Anna's mistakes. "Anna would also get upset with herself for making mistakes, so I have to decide whether I need to tell her about particular mistakes. Managing this is very complex."

> Staff rosters had been very flexible, and boundaries very fluid. But to best manage Anna's work hours, it became important to have fixed days of the week for each person. Anna's manager has assumed more say in setting staff work routines. "I am now in a more managerial role. I am not one of the girls!"

With both issues the ill person's manager adopted firmer management control and better defined management procedures than previously existed in the workplace.

Another survey participant said the changes he experienced "have also impacted on my son, and his workplace. He sat with me during my transplant. He has looked at his life, and decided he doesn't need the level of stress his work placed on him."

During her CEO's illness, Gail says she has grown a lot. "I can do things I didn't think I could. People in the organisation have recognised my worth, and they have a higher level of respect for me. Several of my work relationships have been strengthened. I have also started to look at my family as being more important. My husband and daughter took on more responsibilities at home during that time, and continue to do so. Work-life balance has become important to me."

Part three

BEST PRACTICE ISSUES FOR SUPPORTING A PERSON AT WORK CARING FOR A PERSON WITH A LIFE-THREATENING ILLNESS

'There is nowhere to hide'
(A carer who is Managing Director of a small business)

Accepting, disclosing

This section reports three carer case studies drawn from their interview narratives, then three employer/managers of carers of a person with a life-threatening illness. As with the earlier report of the ill persons' narratives, the focus is on how each person accepts and disclosed their painful or distressing experiences. While the parallel column endeavours to focus on good practice outcomes of meeting needs, there are some instances where the disclosure appears to fall on deaf ears. The report seeks to interpret these responses so that they may still inform the development of a best practice model for support.

Carer of a person with a life-threatening illness
The movement from acceptance to disclosure will now be explored through the interview responses of three people caring for a loved-one with a life-threatening illness.

Accepting painful experience	Disclosing the key to meeting need
Carer (Jenni):	
▪ "Brett's illness hit like a snowball. He couldn't do his shoelaces up; couldn't breathe. He was diagnosed with bowel cancer. I had used up all my sick leave when our daughter was ill and was in hospital in Melbourne for five weeks. "	• "The oncologist told us Brett had bowel cancer, and said, 'there is no hope for you'."
▪ "I would travel from the Shepparton to Melbourne to the hospital, stay all day, then drive home. Nothing got done. I thought they were going to kill him there. I wanted to get him out."	• "I was exhausted. I just focussed on my job. I never cried. I never let work know. I don't know how I drove the distances. I never let work down. I knew what I had to do, and I just did it. I didn't expect them to take on my problems."
▪ "My work environment was poor. They used to scream at me over organisational crap. There was no real training in place. I used to go home hysterical. I resigned from my work as a receptionist a few weeks after Brett's diagnosis, because I had to keep running things at home. Work made me feel demoralised."	• "I tried to maintain a light heartedness in my sadness. After I told my manager about Brett, my relationship with her was better. My manager kept in touch with me. I marvelled over it. She kept in touch and showed their concern. But a lot of people don't give a hoot. They were removed. After Brett died, I told her I hated what she had done to me at work."
▪ "There were times in the past when work had become more important than my family. If I had a job and money, things flowed on for me. This wasn't fair. Brett was too young. His dying was too hard. We did not have enough time together. We never got to talk about it, he died so quick. I had no time."	• "I resigned over the phone. I didn't consider reducing my hours. It was black and white. When I saw him, I knew he couldn't be on his own. I said, 'he is going to die, and I am not leaving him.' I wanted to look after him. He was a grumpy old bastard. We loved him."
▪ "I couldn't look after myself. Food was the worst. Driving to the hospital made me focus, for control. I needed that."	• "My friends cooked. I had takeaways."

- "No one at work can help me now Brett has died. It is in my head. Only I can do this. I am sad. I want to go with him. I was married thirty years."

- "I don't expect anything from anyone. I went to work. I did a job, and got paid for it. But it would be better if work could be supportive of a carer like me, and if there were time out opportunities for self care provided by your colleagues."

This summary of Jenni's interview suggests that working in a poor environment strongly militated against her disclosure of any personal needs she had as a carer. Even though Jenni's disclosure to her manager produced what Jenni regarded as a surprisingly empathetic response, it was not enough to evoke her trust in the work organisation. It seems the emotionally chaotic nature of her workplace rendered work an unsafe place for Jenni to talk further about her carer's role with her dying husband. Instead, Jenni appears to have retreated into the security of the ideological myth about work as a place to be independent and self-reliant, and that through her work she can best determine her future.

Jenni's interview also reveals her capacity for self-disclosure, such as her problem with food preparation and the supportive response of friends, and the disclosure of her suicidal ideas after Brett died. Her openness on these very personal matters heightens the paradoxical nature of her situation. At the end of her interview, Jenni expressed a desire beyond her ideological belief that work provides her security. Jenni wished for the deeper security of supportive work colleagues, especially the need for cooperative work relations to provide time out from all the stresses of being a carer and working.

Accepting painful experience	Disclosing then meeting need
Carer (Ross):	

- "I am half owner of this business, and Managing Director. My brother died from cancer of the liver when he was thirty-nine years of age. I only have one opportunity to deal with my brother's death. If people can't cope with that, I still have other opportunities to deal with them."

- "I needed to be strong with my business partner in setting the ground rules for my needs. Then we all knew where we were at. I needed to keep an eye on the business but its importance dropped. This gave me space to feel my way through the situation."

- "My father suicided when I was young. So my family is used to dealing with these issues. The dying process can cause deep changes in philosophy and values, and this can be upsetting for those around because they don't expect it."

- "I have learned from personal experience that death holds no fear. This gives me a certain self-confidence. There was a need to negotiate roles in the time my bother was ill, and after he died because of the changes forced on me by this situation. I attended the Gawler Foundation with my brother."

- "I told the four key people in my business straight away of my brother's illness. They needed to know so they could understand I wasn't going to be as available as usual. These are moments of truth. They put the business owner's credibility on the line, both personally and for the business. It is a critical time for business. There is nowhere to hide in these moments. You do the best you can."

- "If it was appropriate, this information could then be passed on to other staff. I have trusting relations with my staff, and they picked up what they had to. It was good to learn I could allocate work to my staff and trust them to do it. My focus on the business was not as high. The caring role rightly takes a lot of emotional and intellectual strength. You need to allow the emotional stuff to be sorted first. My openness strengthened my relationships with my partners."

- "I needed to take lots of time off. I flew to Sydney every two to three weeks."

- "This was not a time for 'dealing' with death, but accepting death. Some people's views of heaven and hell lock them into a bad space. My tolerance for small business problems disappeared."

- "I was not the principal carer as my brother was in Sydney. There was practical discussion about how the ill person wished to communicate with others. I worked with my other brother, who monitored how things were for my ill brother. Managing people around the ill person is a key issue. It is important to support the ill person to manage their dying. I am not over-awed by death."

- "Family members took on different roles. I provided the financial support for him. Money clears stuff, and then you can deal with all the other things. Because I was able to be fully present to my brother during this time, I was able to move on after he died. I was also able to help people find their level in their own time. It requires an ability to eat a lot of anger – the strength to not take it personally, and not allow people's anger to spread. It is very heavy work."

- "The most difficult thing for me was when it became clear to me he was going to die. Once that sunk in, I found it difficult to converse with him because I didn't want to extinguish his hope. I wondered whether my bother had everything tied up in his personal affairs."

- "There is a need for a facilitator to lead the conversation with the employer, and then with the employer and ill person, to step down into deeper issues through the interview. There is also a need for a framework for the employer to deal with the issues."

- "It was an opportunity to live out my values. I showed that my brother is important to me, and as a business, I would help you in the same situation. I gained a lot of respect."

- "There is personal credibility for me in living in the grey space of the situation. I say to staff, 'I don't want you to be perfect, I want you to be honest.' I had a couple of young staff I was working with to develop their life habits. I told them I was not abandoning them. They knew the situation with my brother was my priority and they were shuffled down the list."

- "I could ask my brother, 'what support do you need?' Then I would tell others what he needed. This helped my brother keep a level of control. It is the same in business. It was important to control the flow of information, and give people information about the ill person and their illness. I needed to confront a few people and make them aware of what my brother needed, not just what they had to offer."

- "I take a humanist approach to life and business. If you look after people, it will then generate business and money. This is important in running a business. My role is to absorb other's anger, and limit the avenues for it spilling out. You need to stop the ripples. My example gave staff a lot of confidence in handling pressure times – that they can handle pressure in the business or in their own crises."

- "As I watched him dying, I saw he had attended to his personal affairs. I needed to trust this awareness."

- "The facilitator role releases the pressure on the employer, to have someone to share the responsibility with. It is a resource that needs to be made available as required over time. It would be valuable to have a recruitment agency with emotionally mature people who can come in alongside the employer and slot into a job"

This summary of Ross's interview highlights the complex interaction of personal and business needs when the ill person's carer is an employer. The twin burden of these responsibilities gives extra weight to the need for an external consultant to support the employer negotiate their way through them. The need for a framework to assist employers with carer responsibilities to manage the various and competing needs upon them is also supported by James and Friedman's U.S. research, which states that "executives acknowledged that they made decisions during the time span that they were affected by the death of a loved one, that they would never have made under different circumstances."[26]

Ross's experience reveals the way previous experience of death can impact on how people respond to new threats of death – forming emotions, attitudes and awareness that may help (or hinder) effective responses for caring for the ill person, and managing staff issues. In Ross's case, this involved early disclosure to his business partner and setting ground rules for his availability and priorities, informing key people in the business to ensure open, accurate and honest communication with staff, and negotiating with particular employees who may have been vulnerable to the sudden changes in Ross's role.

In this narrative, it is possible to see how Ross's commitment to his brother impacts on his work role, and how Ross's awareness of that impact has equipped him to contain the impact in a healthy way for himself, his family, and his business. The way Ross accepted the growing realisation of his brother's illness and dying became an opportunity for Ross to model emotional maturity, trust, and personal values to his staff. For Ross, these are all vital qualities for the future growth and strength of his business.

Accepting painful experience	Disclosing then meeting need
Carer (Fiona):	
▪ "I am a clinical nurse consultant in a metropolitan health care service. My sister Elizabeth put total trust in my medical opinion when she was diagnosed. She wanted me to attend to any medical decisions that needed to be made. This was all very stressful. I knew the medical prognosis was poor, but I realised the family needed to maintain some sort of positiveness and not give up straight away. I felt she still had a chance because she was very optimistic."	• "Initially I was a support person, not her carer. I became her carer 6 weeks before she died, to relieve her partner. I took leave to care for her, including a month without pay. I was scared at first, but then it was good to be able to give my skills to her. I was able to support my family also. Elizabeth was always so active. She hated feeling a burden because I took time off without pay. I can't believe it's happened. She was accepting at the end. She was sick of it, and wanted to die. Her medical condition was shocking and very stressful. She couldn't stop vomiting and had shocking headaches."
▪ "I told my manager as soon as I knew Elizabeth's diagnosis, and she told the Service manager. When I am at work, I'm work focussed. I am looking for that at work. I prefer it this way. When I am work, I make myself do it. So I have tried to make my situation have as little negative impact on work as possible. I didn't like being asked all the time how I was."	• "I wanted them to know what was going on, and to be informed when I took time out for Elizabeth's medical appointments. Telling her helped my relationship with her to some extent, but it was also belittling and disempowering to have her sympathy. I prefer that if I need to talk to someone then I will find a person I trust."

- "It was very upsetting when my sister rang and I needed to leave work to go to a medical appointment. But if they weren't prepared to give me the time off, I would have left."

- "After I returned to work after Elizabeth died, I realised I wasn't ready, but I had used all my annual leave. I asked the Service manager if I could have leave credits from the coming year, and she refused. Her behaviour is the last straw. I feel my input is not valued. This had a big impact on my finances. I used up my savings in the month I took off. I am down to my last five dollars in my bank account."

- "I am exhausted even now. I just go home, go to bed, and get up and go to work. I am really tired, and I don't sleep. I am sluggish and very sad. I think I am depressed. Her partner wants to move on with his life, and he tells me to let go. I am not ready to let her go."

- "My manager agreed my sister had to come first. This gave me permission to do that. But the consultants needed me to be there for definite times so at first I took a month's annual leave to care for my sister. Some staff offered me informal support in the corridors."

- "She agreed I could take two weeks without pay. She thinks the budget is everything! I am considering relocating from this Service. I intend to give notice after I have found a new job. I may have been moving in this direction any way. All this has accelerated it. I didn't have much support during the six weeks I was on leave caring for my sister. This whole experience changed how I see things. Pleasing people is no longer as important. You have to do what you think is right for your self and the patients you are working for."

- "Once I had used all my entitlements that was it. There was no extending the boundaries. When I feel fragile, I speak to the social worker or pastoral care worker at work. They are willing to give me the time. It would have been good to have someone at work who could provide information to staff who are carers about their own self-care, and who could also give permission to make it happen."

This summary of Fiona's interview highlights how her commitment to being independent ("I prefer to be focused at work"), self reliant ("I don't like being asked how I am"), and able to overcome all that may limit her ("…make my situation have as little negative impact at work as possible") is contradicted by her desire for work to provide her with economic (paid leave credit), emotional (when feeling fragile), information (advice on ways of self care) and appraisal (being valued) support.

Perhaps the needs that Fiona discloses for support at work are not met in part because she is bound up in an ideology of work that is antagonistic to these needs being accepted. However, it is not helpful to blame the victim. Fiona's report of her experience seems to indicate that her views of work are also strongly held within her workplace. Paradoxically, the ideology of work in the health service seems to over-ride the organisation's service philosophy when the carer also works in the service.

Employer/managers of the carer of a person with a life-threatening illness
The movement from acceptance to disclosure is finally explored through the interview responses of three managers/supervisors of employed carers for people with a life-threatening illness.

Accepting painful experience	Disclosing the key to meeting need
Manager (Roger):	
▪ "Michael was caring for his sick wife, Tess. Michael told me about his situation."	• "I felt it was Michael's prerogative to tell others. I took my lead from him."
▪ "As Tess's illness progressed, it had an adverse effect on his ability to work to normal capacity in producing one of our major publications. My relationship with him is more difficult. I found myself withholding my family matters from him, because of my sensitivity about my wife's name being the same as his wife's name."	• "We have not managed very well the impact of Michael's situation on our business. We muddled through and did the best we could. We provided him his normal entitlements. There was implied support from within the organisation."
▪ "Human Resources sent around a memo on how to review Michael's situation. The main cost for our business was the absence of Michael's time and knowledge."	• "Michael was able to take accumulated sick leave plus unpaid leave to cope with Tess's needs. Our HR Department has a high turnover. They could benefit from better training, and may be it would have been handled differently."
▪ "Tess's illness was emotionally wearing on Michael. He couldn't do justice to anything else. I didn't think we needed to discuss how his carer role was impacting on his work, and on others."	• "The leave arrangements for him were the way we provided for his needs. He took about five months carer's leave. Her illness impacted on his personality and strained his relationship with others. He got down, and 'touchy'. There were greater job pressures at the time that led to frustration and tension, which was heightened because of his carer role. There was an informal process. I was following my nose. We had worked together for a number of years, and he had long standing work relationships. Our organisation provides a self-referral no-cost counselling service to staff. The support he was given was fairly high, and depended on different personalities and human variability."
▪ "Since Tess's death, now he is wanting to get more out of his job. Work has become overly important to him, and he is even more sensitive to criticism than he was prior to her illness. I am not sure how others felt about working with him. I don't think anyone was personally affected by his situation. One person didn't add their name to the sympathy card. This was individual behaviour, and not work-related."	• "Michael's carer responsibilities increased the workload on others because there was no other way to cover his work. They took it in their stride, as a given. People modified their behaviour to minimise the impact on him, knowing he was on a bit of a short fuse."

This summary of Roger's interview reveals a business with essentially only two 'catch-all' policies for responding to the situation of an employed carer of a person with a life-threatening illness – a policy for carer's leave, and a policy for individual staff counselling based on self-referral.

It appears the Human Resources Department only provided advice on the leave arrangements, leaving Roger to 'muddle through' a range of issues, including:

- only providing information to staff on Michael's situation by putting the onus back on the already stressed carer.

- his emotional withdrawal from Michael because of his own uncertainty about dealing with a sensitive personal matter.

- not discussing with Michael how his carer role was impacting on his work situation despite the loss of his time and expertise, and Michael's increasingly stressed and then defensive behaviour at work.

- not having a process to support staff who took on extra workload, and de-brief their experience of Michael's stressed and defensive behaviour.

The existing policy appears inadequate to deal with this range of issues Roger identified. So the issues remained unresolved, leaving Roger with the feeling that 'we did the best we could', but if HR were better trained, 'may be it would have been handled differently.'

Accepting painful experience	Disclosing then meeting need
Supervisor (Rachel):	
▪ "Gaye was our receptionist. My CEO rang me to tell me her husband Dave had bowel cancer. I was devastated for her. We were all shocked. Soon after that she left to spend time with Dave. Dave was her life – they were soul-mates, and this makes it worse."	• "It was up to Gaye who she wanted to tell about Dave's diagnosis. Other staff picked up her work. She was our 'front person'. We didn't know how long Dave had to live. There were stresses on staff. We set things in train to employ someone else. We had to employ another receptionist."
▪ "Everyone was supportive. We all tried to cheer her up. She was a valued worker, a loving kind of person. She always wanted to keep busy. She wouldn't let you know if she was down. She wouldn't burden you with her grief. Gaye would go up to the orchards to cry. We were here to work. That was her way. But she felt bad if she had to be away. She didn't want to let anyone down. I could see her frustration, grumpiness and stress due to her overload, and tiredness."	• "There is a balance to personal and professional needs, which is sometimes hard to keep. We each took more on and tried not to burden her. We have a weekly staff meeting. We told her to take whatever time she needed, and we would work around it. We said we would all pull together and cope. The meetings helped people understand, and helped Gaye feel supported and not feel guilty about the changes. She decided to leave."
▪ "We had clashes when she started, but I had a lot on me that has since changed, and we understand each other. As a supervisor you have to keep on people's backs".	• "Because we are smaller, communication is everything. We are offered support if we need it, because in the past a staff member attempted suicide. It was my job to make sure no one was overloaded."

▪ "We didn't have the money to put on extra staff to pick up the load of Gaye's work. And they need training to work in this agency. Gaye's standard of work dropped. A couple of staff found it difficult to maintain their attention to detail. We lost productivity. We couldn't focus or grow. We were just treading water."	• "We all took on extra work. We would never have asked Gaye to leave. She knew the job, and had a good personality. Every one liked her. It was annoying and frustrating for the staff and me because you couldn't fix the problem. The additional workload put more pressure on us."
▪ "My mother died when I was fifteen years old. Since Dave was ill and then died, I have become closer to Gaye. I am recently separated. Sometimes family is more important than work."	• "I tried to be supportive as a friend. I know what it's like. I still ring her. I think about my own life, and what it would be like if it happened to me."

This summary of Rachel's interview shows how porous the boundaries really can be between work and family. Gaye's husband's cancer is the primary cause for Gaye ceasing work. Before she decided to leave work, Gaye's work standard dropped, and the emotional impact of Dave's illness was observed in her work. Rachel's mother's death and her own recent marriage separation lead Rachel to greater empathy for Gaye, and she supported her as much as she could at work, then continued to maintain supportive contact after Gaye left the organisation.

Paradoxically, Gaye also seemed committed to the ideology of work as she struggled to maintain her independence ("she wouldn't let you know if she was down") and self-reliance ("she wouldn't burden you with her grief") at work, to the detriment of her work standard, and increased stress.

Accepting painful experience	Disclosing then meeting need
Manager (Anna):	
▪ "Laura's husband Ryan came into our hospital for a cancer treatment before we employed Laura as a nurse. She was later employed on a short-term contract. I can't fight the battle for Ryan, but if I can help those around him, I will. That helps everyone."	▪ "I knew that in a small community Laura would need a lot of support. When a permanent vacancy occurred and I could see Ryan wasn't well, I sent word through others I would be happy if she applied for the vacancy. It is a good area to work in because my colleague is very good at keeping the group happy. I needed someone willing to learn the job. I encourage Laura to use work as an escape mechanism, to be her self without the responsibility for Ryan. I knew when I took Laura on that Ryan had a life-threatening illness."
▪ "When I was thirty-eight I was very ill and told I had a year to live. I had a six year old. I assume they have been through the same thing. I feel I have a debt to pay back."	• "I told Laura to tell me when she wants time off if she is at screaming point. She can blame me if she needs to. She and Ryan wanted to go to Ian Gawler, then have a holiday. I can change the rosters over night."

- "Sometimes Laura was angry when Ryan was ill, and this causes uncomfortable periods. She was in denial he was dying, and angry with the world. Other staff don't know what to say, or how to deal with it. Some staff expressed concern in the early days about her apparent denial. I talked it through with them. I rely on trustworthy staff to let me know how things are going. Now Laura is cross with Ryan for dying. She hasn't forgiven him. She thinks he is giving in. I am not sure where her anger is coming from. It may be her personality."

- "I don't know if the other staff members think she received favoured treatment. Informally I have talked with my staff about Laura and Ryan's position. I prefer not to have an outsider come in for debriefing. We feel we can deal with it, and there are resource people in the hospital for me to consult with."

- "I try to listen for clues to what my staff are talking about. I may initiate an intentional chat, then listen. I keep an eye open for any resentment or barriers. When she is away, she is replaced on the roster. She only works two shifts per week. Staff say Laura is doing her job. They also present the opportunity to sound off independently of her family. Laura's situation reminds us of our mortality, but we don't want to face it. We talk of birth with joy, but we don't talk about death."

- "I create the climate and culture and hope it can be followed through. I want to give leadership. Older staff that worked with me when I had my time off know where I am coming from. If the nurses don't feel good about themselves, then they won't care well for patients. We need to practice what we preach. It is important to treat each staff member fairly. Our staff supports someone who needs it. The team functions because of the support it gives."

This summary of Anna's interview illustrates the strength and purposefulness she brings to her management role from her own experience of having lived with a life-threatening illness. Anna shows by example she is not fearful in the presence of death, and she respectfully recognised and contained its shadow in health affirming ways. She was clear about her leadership role, and the importance of modelling behaviour that supported a health promoting work culture. A further component of Anna's management was her commitment to trust her staff, and her confidence in their and her resources. Anna was proactive in identifying Laura's needs as her husband Ryan's carer, and acted within existing hospital policies of fairness to create an opportunity for Laura to have job security at a time of increasing upheaval with Ryan's illness. Anna initiated conversation with her staff to ensure feedback on how they were coping with Laura's situation, and intervened to support them with their responses, first to Laura's denial and later her anger.

Elements for a workplace assessment framework

The summaries of the three carers' interviews also establish some of the elements for an assessment of workplace support for a person caring for someone with a life-threatening illness. From Jenni's interview, the elements are:

1.   **Human resource management**
  - more flexible approaches to the provision of sick leave for use by carers;
  - focusing on developing emotionally supportive work environment;
  - development of policies for 'work-home' inter-face issues.

2.   **Occupational health and safety**
  - managing accumulated stress associated with the carer's exhaustion from increased work load at home, and continuing load in their employment.

From Ross's interview, the elements are:

1.   **Human resource management**
  - development of policies that recognise the priority claim on a carer of the ill person's needs over work commitments.
  - identifying staff members' experience with illness, dying and death that may equip them to be resource people for the organisation in dealing with issues arising.
  - development of an information strategy for informing people in the workplace about the carer's situation and changing needs.
  - conducting a risk assessment of the impact of honest and direct communication with staff, and develop appropriate management strategies to support and contain in a safe environment staff responses to the changing situation.

2.   **Health promoting care**
  - encouraging awareness of how the skills and experiences developed as a carer may be transferred to the business environment.
  - establishing clear boundaries that respect the limited claim of work on health promoting human values.

3.   **Meeting production needs**
  - recognising the need for a facilitator to assist the employer construct a framework for managing the competing personal, social and economic needs.

From Fiona's interview, the elements are:

1. **Human resource management**
   - policy for carers needs to recognise that at different times, work may be a means of denial ("If I work hard, everything will be alright."), an avenue of escape from the chaos and confusion caused by their loved-one's illness, or a place to restore the carer's sense of competence and self-worth in the face of their powerlessness and hopelessness as their loved-one's illness progresses.

   - staff need to be informed how the carer wishes to manage conversations at work about their situation, especially if the carer needs work to be an escape or a normalising experience for them.

2. **Occupational health and safety**
   A carer's exhaustion at work, especially during bereavement, may be exacerbated by the workplace failing to acknowledge the carer's grief. The grief is not caused by the carer's work, but the failure to accept it and respond to it at work is likely to increase the risk of the carer's sadness deepening into an occupational illness such as depression.

Interviews with two other carers identified the following issues that may be incorporated into a workplace assessment protocol:

Human resource management
Paul, a project manager in a very specialist area said that after the first year of his wife's illness, he lost confidence she would recover. In the second and third years of her illness, Paul "wasn't very well at work. I was preoccupied. Every day, something was happening to Gail. I was emotionally exhausted." Paul's words echo the finding of a study by the National Health Council USA, that "caregivers find their end-of-life situations very difficult, stressful, and devastating."[27] Nearly thirty years in his job, Paul took his sick leave as carer's leave. He said, "I don't know how I would have coped if I didn't have it." His leave was approved by the HR Department. The provision of carer's leave is a foundational policy requirement in supporting a carer of a person with a life-threatening illness.

A second policy area is the importance to carer's of increased flexibility for work arrangements. Paul tried to work from home for four weeks, but wasn't able to concentrate. That is when he decided to take carer's leave, and went to work when he felt like it, maybe one or two days per week. Working from home was first proposed as a short-term arrangement, and approved by the HR Department. Paul filled out a form to say his home was a safe work environment.

A third policy area is developing a supportive workplace culture that integrates emotional, intellectual and physical aspects of living. Paul became "moody and cranky for no reason" after Gail's diagnosis, and still feels "frustrated, withdrawn, and embarrassed" a year after her death. He says he has been depressed, and "could have talked about my feelings and sought help if I had been stressed, but I was not sufficiently depressed for me to put myself in another person's hands."

Paul said, '"Men don't show their feelings much." He also said he was fearful of being sacked for becoming ineffective. "I didn't want that to happen to me." In traditional masculinity, a personal sense of weakness or failure is often covered up by those who fear it will be ridiculed or punished. So many men resist counselling because it draws attention to their vulnerability. In his interview, Paul recalled another man who had "left - was he sacked?" - because he had become less effective at work. When Paul returned to work after Gail died, a number of people who didn't know he had been on carer's leave told him they thought he had retired. Paul had worked quite hard to hide his vulnerability, but there appears to be an ongoing cost both personally and for the organisation in terms of his defensive and withdrawn behaviour.

The unresolved and unacknowledged state of Paul's emotional response to his situation may be the catalyst for his thoughts of resignation. At the time of interview, Paul said his work was "absolutely, monumentally important and frustratingly enjoyable" to him, and his work was snowballing. Yet he also said he had always been "a bit touchy", and was now "more vulnerable to comments. Sometimes I feel I am not as secure as I was." Paul believes he will retire in a year's time, and maybe take a part-time job he has been asked to consider. Paul's resignation would represent a significant loss of expertise and market advantage to his organisation.

A significant challenge in supporting a carer at work is being understanding of the carer's anger, and responding empathetically to their anger. This may be more difficult in work environments that value rational and efficient behaviour. Michelle works as a hospital nurse, and has been angry that her husband Adam's illness was not diagnosed for two years because "Adam's doctor told him to put cream on his shoulder. Now he will eventually die." "People have told me not to think this way," she said, "I feel like the world is caving in." Michelle said, "I get very angry and that doesn't help. Sometimes at work it is too much to cope with. I would try to be rational."

Treating a carer like other staff at work may also empower the carer. Michelle's work colleagues are supportive and understanding. She says they have all had drama in their lives. "They ask me for my thoughts on things if there is a cancer in their career or their life. The life experience of co-workers has also helped me." Michelle is not treated as a helpless victim in these conversations at work, even when she may at times feel helpless about Adam's illness. By talking about her experience, Michelle appears to draw comfort from seeing both personally and professionally that she is helping someone else to face what she has so far gone through.

Occupational health and safety
• Tiredness from carer responsibilities at home can cause a hazard at work. Once the hazard has been identified, it is important to eliminate or minimise its risk. Michelle has found concentrating at work difficult, but her work colleagues "have guided me through". Her ability to concentrate was affected by lack of sleep from worry, and driving to Melbourne and Ballarat for treatment from the country town where they lived.

Health promoting care
In the trajectory of a person's caring role, work may play an important health promoting role for them. For Michelle, work "is an outlet. I enjoy my work. I love my work. I can't sit here and watch Adam getting worse. Work is time out. I can be me there. Now I feel really comfortable at work. I feel awkward within myself dealing with it all, but my boss and co-workers have been fine. My boss has been down this path herself."

A health promoting work environment also may have benefits for the well-being of the ill person because they may draw comfort from knowing their carer is being supported at work. Michelle's boss' support means a lot. "It gives me stability, and I feel worthy. Overall, I feel part of the team. My boss makes me feel secure because she is so obliging. It also helps Adam feel secure too. He knows I enjoy my job."

The summaries of the three managers/supervisors interviews also reveal some of the elements for an assessment of workplace support for a carer of a person with a life-threatening illness. From Roger's interview, these elements are:

1.   **Human resource management**
       The absence of any workplace policy for responding to carer's needs at work apart from leave policy means most of the initiative for responding to those needs becomes the responsibility of the carer, who is already overloaded with the needs of the person they are caring for.

       The absence of HR policy for a carer may leave areas of uncertainty and discomfit for many work relations, contributing to the social isolation of the carer.

       HR policy needs to incorporate ongoing professional development of HR staff in dealing with carer needs, and contributing to policy development.
       A workplace's provision of self-referral counselling is only part of a comprehensive policy framework for meeting carer needs. On its own, such a service may be seen as a symbol the workplace doesn't want to deal with carer needs, and is available for those not strong enough to cope, that is, it turns the normal experience of struggling with illness and dying into a problem for which only experts can help.

2.   **Meeting production needs:**
       Management needs to assess the capacity of the workforce to cover the loss of production due to absences of a carer, then decide (in consultation with those affected) how these needs may be best met.

From Rachel's interview, the elements to be considered in assessing the needs for carer support are:

1.   **Human resource management**
       The regular staff meeting was a valuable means of assessing how staff members were coping with increased workloads to support the carer's absences.

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2. **Occupational health and safety**

    When the carer feels they have to leave the workplace to cry because they believe the workplace is for work, it is likely to indicate the carer believes the workplace is not a safe place for direct expression of their emotions. These emotions may then be expressed indirectly as grumpiness, frustration and stress.

3. **Meeting production needs**

    The pressure of increased workloads from carer absences and the indirect expression of strong emotion due to the prevailing work culture may cause staff to be distracted with their work, and lose their attention to detail, reducing productivity.

From Anna's interview, the elements to be considered in assessing the needs for carer support are:

1. **Human resource management**

    Job security is an important issue for carers in supporting them to focus on the needs of the ill person. It is important to identify managers and staff who can be resources for others because they have lived through experiences of illness, grief and loss and are willing and able to support the carer, as well as provide information and emotional support to other staff to strengthen their capacity to contribute to a supportive work environment. Carer's anger is a normal part of their emotional response to their loved one's illness and their own sense of powerlessness. Managers can support such staff by creating a culture of acceptance based on empathy with the carer's feelings, and encouragement of the carer to be involved with their work in ways that are empowering.

    Carer policy may need to emphasise the value of fairness in the support or concessions that are offered, and ensure open feedback from all staff who may experience resentment or work overload.

    A carer policy may benefit by clarifying how the policy expresses the core values of the organisation and strengthens the integrity of the organisation.

An interview with a carer's work colleague identified the following human resource management issues that may be incorporated into a workplace assessment protocol:

    An important HR policy matter is managing the information around an employed carer's situation. Debbie was told about her co-worker Michelle's situation "when someone said something, and that is how I knew." Debbie said she "felt awful. I felt really sad." This response highlights the difficulties that can arise when information is passed on informally. Debbie says her work relationships are based on caring for each other as nurses. This is what makes her work enjoyable, and is the foundation for working well together. Yet information that is passed on informally makes the two nurses work relations unequal, because Debbie now knows something about Michelle that Michelle does not know that Debbie knows.

The emotions this information raised in Debbie may also become a barrier to their communication, causing social distance in their relationship and creating further stress for both nurses. This practice of informal communication may then set the power relations between staff for the duration of the carer's role. Debbie explained, "I always pick my time to ask how Adam is. I leave it up to her to bring up anything. She comes in more closed sometimes."

When caring staff members are unsure what to do because there is no policy framework for their supportive action, they are likely to do nothing, as in this case, and then justify their action as respecting the carer's autonomy. In fact, the ambiguity of such situations and lack of engagement is more likely to reinforce the carer's sense of helplessness, causing social distance and increased stress for both parties. U.K. researcher Charles-Edwards states that "colleagues and supervisors who are aware of the caregiver's situation often provide words of encouragement and gestures of support. Agreement is needed on what to say, to whom, and under what circumstances."[28] Charles-Edwards suggests that colleagues who understand the reasons they are being asked to support another employee through change of role or responsibilities are more likely to remain generous in spirit when the burden of work and support gets tough.

Truth and honesty may be vital values to be embodied in an information policy because they encourage direct communication. They also give shape to a work culture that is intentional about being supportive. Debbie concluded her interview saying that workplaces would be better equipped to respond to carer's needs if they "acknowledge publicly that this is your reality", and supported the role of work friends who "can be true and honest. Some things that need to be spoken about are not nice."

Elements in the sequencing of support

The support needs of carers may be conceptualised in a similar way to those of the ill person. In a manner similar to the report on the best practice of support for ill persons, the carer interviews do not reveal one pattern of support that fits every occasion. Similar reasons for the observed differences in workplace responses to a person with a life-threatening illness have also been observed with workplace responses to carers.

The research material reported to this point in part three does not highlight any new support issues for emotional, information and appraisal support for carers from those issues identified in part two on sequencing support for the ill-person. The one aspect of support for carers that warrants further reporting from our research is the provision of economic support for carers, and this will be considered next.

Economic support: some issues

Income maintenance
One of the carers had used up all her sick leave caring for an ill daughter, so when her husband became seriously ill, she had no leave available to her. Within two weeks of her husband's diagnosis, she resigned her job and applied to Centrelink for a Carer's Benefit. Another carer was only able to access a few days compassionate leave, so after using that and her annual leave, she had to take leave without pay until her sister died.

Three other carers accessed accumulated sick leave to maintain their income during a loved one's illness. At different stages, several carers also worked reduced hours mixed with time on sick leave.

One carer reported she used all her savings during the time she could not work while caring for her dying sister, and another who resigned from work lived the last harrowing month of her husband's life on income from a Centrelink benefit.

Costs and benefits to the company
One company manager said the main cost to his company during the carer's absence was the loss of his time and specialist expertise. He did not identify any benefits to their business in continuing the carer's employment during the time he was caring for his ill and dying wife.

Another manager thought the main cost to their organisation was during the time the carers was balancing work and carer responsibilities. This required a commitment of energy by other staff to deal with the carer's emotional distress. The manager said they benefited from the carer's knowledge of the job and her personality. By continuing to support her employment, the organisation also saved on training costs for new staff.

Where the carer was employed on part-time shift work, her manager said there was "minimal cost" in maintaining the carer's employment. The organisation's roster system helped them cover shifts that could not be worked when a staff person was ill, and this was used to cover times when the carer was unable to work. The manager said the organisation benefited by continuing the carer's employment because staff "have a sense of supporting someone who needs it. It gives them comfort and a good feeling, and strengthens the team function."

Other economic issues

Other economic issues for industry arising from this research with carers and their employers/managers have been documented in the section on 'Assessment framework', especially in relation to production needs and occupational health and safety.

Part four

A SUPPORT MODEL FOR AUSTRALIAN WORKPLACES:
INVITATION TO BEST PRACTICE

'Not pressured to finish everything each day'.
(Person with a life-threatening illness)

The best practice support model for Australian workplaces wishing to support a person with a life-threatening illness or an employed carer will ultimately be judged by those who adapt the insights gained from this report to their own situation.

The insights from this study suggest a best practice support model will incorporate elements of the following framework:

BEST PRACTICE SUPPORT MODEL
WORKPLACE SUPPORT FOR LIFE-THREATENING ILLNESS

AIMS
To equip workplaces to respond to the needs of

*employees living with a life-threatening illness
*employed carers
(from point of diagnosis through to resolution of bereavement.)

The support model will address:

*the provision of information
*training needs
*HR and OHS Policies
*creative support strategies

for living with a life-threatening illness for:

*The employee
*The employed carer
*Managers
*Colleagues
*Families.

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BEST PRACTICE SUPPORT MODEL
WORKPLACE SUPPORT FOR LIFE-THREATENING ILLNESS

PROCESS

CRITICAL CONVERSATIONS
Identify workplace issues and needs
Manager – Ill Person/Carer – one other e.g. colleague

WORKPLACE ASSESSMENT
Assess workplace support needs
and current or potential risk factors
HR Management Issues
OHS Management Issues
Health Promoting Care Issues
Production Needs

POLICY AND PROCEDURE
Identify and implement
workplace support policies and strategies.

RESOURCES
Inform and guide workplace support
decisions and practices
to gain improved understanding of support needs**.**

TRAINING
Inform and educate workplaces in
support policies and
grief, loss and bereavement guidelines and strategies
to improve understanding about illness and disease and
'palliative approach' support resources & services.

CONSULTANCY, ADVICE AND SUPPORT
Provide information
Link with external support, information and resources
Undertake workplace assessments
Advise on policies and strategies
Offer support and advice
to managers/employers and employees
(includes any identified internal Support Role).

Endnotes

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