

A Literature Report on
Developing a Best Practice
Support model for Life-threatening
Illness in the Workplace

By Mary Tehan

Department of Health and Ageing funded
Caring Communities Project

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on
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SECTION 1

What does the literature tell us?

Background

The Australian government has funded a two and a half year project, under the Commonwealth Department of Health and Ageing *Caring Communities* program, to develop a Best Practice Support Model for Terminal Illness in the Workplace. This project is auspiced by Palliative Care Victoria in partnership with the Creative Ministries Network, an agency of the Uniting Church of Australia.

Key project objectives are:

- to develop a Support Model framework;
- to develop policies and strategies for a Best Practice Support Model to provide support in the workplace for a person with a terminal illness;
- to improve support for the dying person in the workplace;
- to improve the support by the workplace for an employed carer of a dying person;
- to develop policies and strategies by the workplace that are supportive of an employee who has a key role in the care of a relative with a terminal illness;
- to integrate the role of palliative care with workplace.

These objectives will therefore be used to guide the literature report, inform the development of an appropriate research design and methodology to research the incidence of terminal illness in the workplace, and frame the development of an appropriate Australian Workplace Support Model for terminal illness.

The purpose and scope of this literature report

is to provide:

- evidence of previous studies relating to research about support needs for terminal illness in the workplace;
- key messages from previous research and relevant secondary sources, including reasoned argument and legislation.

It should be noted that, until now, there has been a minimal amount of Australian research relating to terminal illness support needs in the workplace.

The literature identified in this report supports a Best Practice Support Model for *Life-threatening Illness* in the Workplace, rather than for *Terminal Illness* in the Workplace. Literature has been sought about people living with a life-threatening illness or serious chronic illness and, as most people live in hope that their illness will be cured, at a much earlier stage in the trajectory of the

illness experience. Existing Australian palliative care literature has focussed primarily on end-of-life issues in the terminal phase of a person's life when employment is not possible or when the carer has already ceased work to care for the person who requires palliative care support. Attachment B outlines relevant definitions used throughout this report.

The need for end-of life support in the Australian workplace

As Australia has an ageing population, it appears extremely likely that there will be a shrinking of labour supply in the future. As acknowledged by the Federal Minister for Employment and Workplace Relations at the Pursuing Opportunity and Prosperity conference (2003), flexibility and choice around family-work arrangements will need to be considered in policy *over the life course* (Andrews, Hon. K., p. 4). However, end-of-life (workforce and workplace) support needs have not yet become part of the conversation amongst key employer bodies, policy makers, and politicians at either a State or National level. Nor are there any provisions in the *Australian Workplace Relations Act 1996* that address work-family responsibility for end-of-life care in its own right. The Victorian Workcover Authority (2005) also fails to mention life-threatening illness, loss, grief or bereavement in its *The Return to Work Guide for Victorian Employers*.

A report on the *Social Impact of Caring for Terminally Ill People in Australia* (Aoun, 2004) notes that carers have suggested the need for "flexibility and understanding in the workplace" to enable them to carry out their carer responsibilities with adequate support (p. 51). This statement is the first piece of evidence documented in Australian palliative care literature that directly relates care needs to work and places it in a social context.

Canada is addressing the need to support its workforce when an employed carer is supporting a person who is gravely ill. Compassionate Care Benefits are available for unpaid care-givers to relieve pressure on families and on the health care system. These benefits allow informal carer-givers to take time off work under Canada's Employment Insurance program. With evidence of a medical certificate and within certain criteria, employees can take up to six weeks leave from their work to care for a gravely ill family member (a person with a significant risk of death within twenty-six weeks) under the Canadian Employment Insurance Act and Regulations 1996 (Compassionate Care Benefits, Canada, 2004; Kirby & Romanow Reports Canada, 2002). The Canadian government has also made amendments to the Canada Labour Code to establish entitlement to a period of leave up to eight weeks duration with job protection within a twenty-six week period, for the purpose of providing compassionate care to a family member (following adoption of the Budget Implementation Act, Bill C-28, Parliament of Canada, June 2003).

The economic impact of inadequate support

Two issues that have been consistently identified in international workplace literature, impacting upon employers, are loss of productivity and loss of profitability (AHF, USA, 2000; James & Friedman, 2003, USA; and Charles-Edwards, 2000, UK). When grief and loss are recognised and addressed in the workplace through comprehensive grief programs, companies encounter

fewer mistakes and improved morale, use less sick leave, experience lower staff turnover and better teamwork, and productivity is sustained (AHF, USA, 2000, p. 3). Some policy considerations worth noting are outlined in the Policy and Strategies section of this report.

In the USA a survey, titled *The Grief Index: The Hidden Costs of Grief in America's Workplace*, estimates that the total annual hidden cost of grief at work to business is \$US 75.1 billion (James and Friedman, 2003, p. 4). The death of loved ones is estimated at \$US 37.5 billion and the death of extended families, colleagues and friends is estimated at \$US 7 billion (p. 4). James and Friedman (2003) argue that the costs to workplaces are, to a large extent, avoidable through heightened awareness and some simple, practical shifts in communication (p. 9). They state that "grief is emotional not intellectual" and they assert that, throughout the USA and most other cultures, constant efforts are being made to shift people from their emotional truths to intellectual positions that diminish or alter the normal reaction to the loss (p. 9).

Charles-Edwards (2000) asserts 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" (p. 141). Factoring awareness-raising and emotional intelligence strategies into a Best Practice Support Model may improve support for managers and their employees trying to deal with life-threatening/terminal illness in their workplace.

Changes in tasks and relationships may need to be negotiated on an ongoing basis to ensure that work can continue through peaks and troughs in business productivity cycles. Arrangements can be modified to assist the workplace to continue to meet its responsibilities without destabilising the business or its workforce. These arrangements include hours of work, work roles and types, levels of workplace responsibility for the employer, colleagues and the ill employee or employed carer (Grierson et al, Australia, 2002); CancerBACUP, UK, 2005); and Last Acts Taskforce for Last Acts Campaign, USA, 2003).

Of particular importance to government, employer bodies, businesses and policymakers, identified by James and Friedman (2003), is the impact on the workplace when an executive is affected by a death of a loved one. Their report states that "executives acknowledged that they had 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" (James and Friedman, 2003, p. 23). They also indicate that by the time errors were discovered, serious damage had already been done. The implications around support needs for the businesses in this situation would be worthy of separate research in the light of the profound impact that grief could have on a workplace that finds itself facing grief, loss and bereavement in its managers.

Given that most Australian companies are small businesses (Hanrahan, Ramsay and Stapleton, 2002; ABS, 2004), serious consideration needs to be given to dissemination, education and training into the Small Business arena if productivity and profitability issues due to life-threatening illness, employed carer responsibilities and workplace grief, loss and bereavement are to be addressed (p. 6). Small business counselling services and networks may be the most useful vehicles for dissemination of the components of a Small Business Owner's Support Model. Practical issues such as maintenance of production needs would also require consideration in formulating an appropriate model of workplace support.

Illness to be understood in its social and cultural context

People with a life-threatening illness (and carers) have needs that may require support at different points along the illness and bereavement trajectory (National Institute for Clinical Excellence, 2004; National Health Priority Action Council, 2004 as cited in Strengthening Palliative Care: A Policy for Health and Community Care Providers 2004 – 2009, p. 4). The same issues and needs may equally apply when these people are in employment or are seeking to return to work (National Institute of Clinical Excellence, 2004, p. 11).

Kleinman et al. (1978) note that “modern physicians diagnose and treat *disease* (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.”, p. 251). The illness experience, according to Kleinman et al (1978), “is an intimate part of social systems of meaning and rules for behaviour, is strongly influenced by culture and is therefore culturally constructed” (p. 252). Illness may have one of four psychosocial meanings: threat, loss, no significance or gain (p. 256) and according to Charmaz (1983) illness can amount to loss of self through leading a restricted life, experiencing social isolation, being discredited or burdening others. Ultimately people describe and order, through narratives, their illness (Kleinman 1988) and their understanding of their life process (Anderson and Foley 2001). Broadly speaking, illness must be understood in its cultural context (Charmaz et al. 1997).

Indeed, in the editorial of the *Social Networks* newsletter, palliative care needs to be provided wherever people with life-threatening illness live out ordinary and everyday parts of their lives (Kellehear, Editor, 2003, p. 1). The workplace is one such part of people's everyday lives. Principal reasons why, for example, HIV positive people returned to work after treatment, according to Grierson et al. (2002) were for self-worth, to be useful, and for financial and social reasons (p. 89). The importance of social support and social networks in the context of health should not be underestimated (Janes, Stall & Gifford, 1986) and “those who have the greatest need of social support are, frequently, the least likely to get it” (Avery, 2002, p. 2). Health-promoting palliative care (Kellehear, 1999) identifies social supports and environmental and policy development as fundamental tenets of good end-of-life support

(p. 22). Integrating health-promoting palliative care into the workplace would assist employers to keep their ill employees or employed carers of a dying person socially connected to, and within, their workplace.

Stigma & discrimination attached to the illness experience

Stigma towards any person who is grappling with a life-threatening/terminal illness has the potential to exist wherever there is a perception of 'otherness and difference' and may emerge at any stage along the illness or bereavement trajectory during work-time. Link & Phelan (2001) apply the term stigma "when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold" (p. 367). Where as Alonzo & Reynolds (1995) note that:

stigma devalues individuals who possess the mark and substantially reduces life chances by reducing the humanising benefits of free and unfettered social intercourse (p. 313).

Alonzo and Reynolds (1995) also suggest that the experience of stigma can be expansive, pervading all corners of one's life space and identity and therefore employers need to recognise the emergence of stigma in their workplace and feel able to deal with it competently (p. 313).

The very presence of palliative care support in the workplace may actually intensify stigma and discrimination for the ill person or employed carer. Therefore careful consideration needs to be given as to whether direct involvement of palliative care support in businesses would be worthwhile or whether it may compromise employer-employee integrity. External support may require links to be developed between the following domains:

- grief, loss and bereavement support;
- pastoral care support;
- human resource management/occupational health and safety (risk) management;
- health promoting palliative approach awareness and support; and
- death education.

Platt & Gifford (2003) outline some strategies that would assist employers deal with the social stigma of employees with HCV. Two strategies are identified through consultation with an employment agency as part of the study and include:

- working with employers to help them understand the distinction between 'illness' and 'the kind of person' who is thought to have this illness
- the systematic incorporation of specific information about living with and working with HCV into counselling and support and services for people with the virus (p. 186).

Platt & Gifford's (2003) study highlights that potentially discriminatory behaviour is brought about not so much by ill-intent but rather ignorance about the particular illness.

Businesses too are questioning the age-old distinction between work and the personal: “companies are realising they can’t separate employees; work and personal lives” (AFR 2005, p. 59). Employers therefore need to ensure that their workplaces can embrace the tensions between integrating work and personal life and separating out an illness from the ‘kind of person’ the employee is.

Magee (2004) has studied the effects of illness and disability on job separation and concludes that the decisions of workers may affect voluntary job separations. Keeping colleagues informed as the situation changes may therefore be a very important consideration in the interest of retaining employees. Magee (2004) highlights that there is a need for more research to be undertaken as to “why disabling illness has a negative effect on layoff, while illness in the absence of disability increases the hazard of layoff” (p. 1134). Magee suggests that one possibility for this apparent contradiction is that “workers with long-term work-related disabilities tend to hold jobs where their disability is accepted, accommodated, or legally protected” (p. 1134).

A culture of acceptance of ‘otherness and difference’ may therefore need to be encouraged and protected through policy guidance (ILO 2001, SMARTWork 2004, DAS 2005, CAS 1986, SPB 2002) or legislative means such as the Canadian Employment Insurance Act 1996. This will assist employers in their task of supporting their workplace when an employee has a life-threatening/terminal illness or is an employed carer.

Boundaries of confidentiality and the dilemma of disclosure

An employer needs to be aware of the health status of an ill employee and/or employed carer to be able to decide on, and implement, appropriate workplace support policies and strategies. Charles-Edwards (2000) states that “colleagues and supervisors who are aware of the caregivers’ situations often provide words of encouragement and gestures of support” (p. 72). This statement implies that effective support by an employer and workplace colleagues may be contingent on disclosure of the employee’s illness diagnosis or carer status to their manager and work colleagues. Temporary or permanent cessation from work may need to be negotiated and agreed to when an employee has a terminal illness. An employed carer of a person with a terminal illness may also need to negotiate their return to work during the bereavement period.

According to Charles-Edwards (2000) “agreement is needed on what to say, to whom, and under what circumstances” (p. 72). The ability to discern and negotiate appropriate levels of disclosure and/or confidentiality is an important management skill when dealing with employees and workplace support issues and needs. Boundaries around confidentiality need to be clear, for there is no justification for forcing disclosure by workers or co-workers (ILO, 2001, p. 4). 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 becomes difficult (Charles-Edwards, 2000, p. 72). Kathryn Tyler (2003) cites Schoeneck, Executive Director of Hope for Bereaved Inc., Syracuse, USA

who states that “if the work is redistributed, it’s very important to include all co-workers in the decision, rather than just do it, which causes resentment” (p. 4). Creative and inclusive communication strategies may therefore need to be implemented to minimise the risk of other valued employees terminating their employment as a result of misunderstanding and unresolved resentment.

Disclosure and confidentiality issues can be fraught with misunderstanding if left ambiguous in the workplace environment. Twenty per cent of people living with HIV/AIDS who participated in the study by Grierson et al. (2002) expressed unwanted disclosure of their HIV status by work colleagues (p. 57). Unwanted disclosure can have impacts on emotional safety at work, job security and the maintenance of workplace co-operation and productivity. Gossip and explaining absences from work were the two most common difficulties for HIV positive people wishing to maintain confidentiality at work (Grierson et al, 2002, p. 90).

Platt & Gifford (2003) explore whether employers would hold “negative perceptions about employees with HCV (Hepatitis C Virus) and whether employers would be less likely to hire someone with HCV, all other things being equal” (p. 184). Results from this study found that, “even though there was no legal obligation for people with HCV to disclose their status, employers indicated that they were less concerned with legal issues and preferred to have trustworthy people as employees”. These employers argued that they saw “disclosure as a type of risk management” (p. 184). This study highlighted that social stigma was a key barrier to improving knowledge about the virus and overcoming sources of discrimination for those people affected by HCV (p. 185).

Grief, loss and bereavement in the workplace: an OH&S issue

Grief can be described as a workplace taboo (Aoun, 2004, p. 56). If the stigma of a terminally ill employee (or an employed carer) is combined with the taboo of a grieving employee/s, the situation can be fraught with misunderstanding and ongoing emotional struggles. Paradoxically while grief is a taboo in the workplace, the fact that more people suffer work-related deaths than die on the roads (Ellis, 2004) suggests that grief, loss and bereavement are actually being faced frequently at work and are generally addressed as occupational health and safety issues (cited by Tippett in *The Age*, 2005, p. 6).

Renzenbrink (2002) notes that it is important to recognise that losses are complex and rarely limited to a single event. Grieving is a process of adaptation and the word ‘bereavement’ conveys a sense of a person being deprived, of having something stripped away against one’s will, of “being robbed” (p. 1). Marris’ (1974), cited in Renzenbrink (2002), suggests that bereavement shatters our “structure of meaning” and “breaks the thread of continuity that makes the world intelligible” and expresses a belief that it is through the grieving process that shattered structures of meaning are repaired (p. 8). It is in this context that grief manifests itself as an ‘ache’ that accompanies the grieving person wherever they are, including at work. An effective Support Model for Terminal Illness in the Workplace will need to address the ‘ache’ component to be useful and relevant to employers and

employees. Grief and loss, manifesting as shock, disbelief, and numbness, may impair an employee's judgment at work. Side effects of medical treatments, undertaking ongoing carer responsibilities, and work colleagues undertaking extra tasks to support each other may also result in employees feeling tired, distracted and moody with a potential negative impact on business productivity (Workplace Taskforce of the Last Acts Campaign, 1999, p. 32). Reduced concentration may impact on an ill employee's/employed carer's/burdened colleague's ability to undertake their tasks at work competently. These impacts may eventually arise as serious occupational health and safety issues unless identified and addressed.

Some Australian employment contracts allow up to two days bereavement leave to cover any grief and loss needs when an employee's loved one dies (*Metal Engineering and Associated Industries Award*, (Section, 7.2.5 (a); and *Award AW796561 Social and Community Services – Victoria*, 2000, Section 33.5. Both Renzenbrink (2002) and James & Friedman (2003) establish that the process of grieving involves emotional repair work that takes time and may take years of recovery. Two days bereavement leave implies that an employee can 'get over it', 'move on', 'get back to normal', 'put it behind them' when the research clearly identifies that this approach to grief and bereavement support may be profoundly inadequate. A more flexible approach that permits discretionary bereavement and/or compassionate leave to cover the first year 'on an as-needs' basis could give the message to the bereaved employee and their work colleagues that grief needs to be responded to as it is worked through and experienced. Many different cultures and faith traditions would also benefit from this flexibility as some rituals and ceremonies are honoured at different times throughout the first year of bereavement.

The employer

The employer is pivotal in providing appropriate workplace support to an employee living with a life-threatening/terminal illness and/or an employed carer of a person with a life-threatening/terminal illness.

The USA Last Acts Workplace Task Force *Research Findings from Studies with Companies and Caregivers* states that, in the interests of providing effective support, management need to know:

- what benefits and resources are available to employees; and
- how to - access these resources;
 - respond to employees who ask for help;
 - facilitate leave time;
 - facilitate a special work schedule;
 - facilitate a temporary re-distribution of responsibilities (1999, p. 15).

This study also states that companies would want their managers to handle the situations sensitively, consistently and confidentially (Last Acts Taskforce for the Last Acts Campaign, 1999, p. 24). Employers concerns such as "cost, employees potentially taking advantage of policies, creating a paperwork

nightmare, the inability of one policy to deal with individual situations, and having other more important benefits to concentrate on” were all cited by participants in the study (Last Acts Taskforce for the Last Acts Campaign, 1999, p. 24). It is critically important that the responsibility for support needs be shared between employer and employee, and between employees.

Charles-Edwards suggests that colleagues try to find creative ways to care for themselves and each other within the parameters of their roles and responsibilities (2000, p. 73). As part of a support strategy and process, managers may also need support to articulate their own needs through sharing their sometimes confusing feelings (2000, p. 73). Charles-Edwards identifies 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” (2000, p. 77). This concern may be just as immediate for an employer as for an ill employee/employed carer’s work colleagues and may need to be taken into consideration when outlining policies and strategies for the Support Model. Regular review and discussions about working adjustments or flexible working arrangements need to be adhered to between the ill employee and their manager (CancerBACUP, 2005, p. 30). This approach would mean that both the employer and the ill employee would meet regularly, hence the ability to handle discomfort about grief may need to be incorporated into a manager’s skill profile.

An effective employer, argues Charles-Edwards (2000), understands the role the workplace can offer in supporting an employee through the grieving process (2000, p. 9). This role represents part of the wider society, provides a context for mourning, can sometimes provide an escape from grieving, and can be a bridge between grief and returning to ‘normality’ (2000, p. 9). Sohmen (2004) suggests that “most people would appreciate a leader who is willing to be humble and selflessly serve the best interests of the followers” (p. 3). De Pree asserts, in *Leadership is an Art* as cited in Sohmen (2004), that “the first responsibility of a leader is to define reality” (pp. 7, 9). Simply, humanity must be balanced with meeting production needs. Sohmen (2004) also identifies elements of a leadership style, known as ‘servant leadership’, that “emphasises increased service to others; an ethical-spiritual base; a holistic approach to work; promoting a sense of community; and the sharing of power in decision-making” (p 9). Employers may embrace such a style of leadership by placing the ill employee or employed carer at the centre of their decision-making during the employee’s period of vulnerability. Employers could facilitate this reality through appropriate and creative policies and processes that reflect mutual respect in their workplace. In order to maintain productivity and manage all the elements of workplace support for employees, managers may also need to consider creative ways to care for themselves. A Best Practice Support Model will recognise this need and identify strategies to support managers who find might themselves facing such complexity whilst carrying out their responsibilities.

Person-centred support

Lynn (1999) identifies that:

although society expects patients to die in a predictable and timely fashion, most people will not have a predictable timing of death, nor a few weeks with visibly declining health just before death (p. 4).

Altschuler (1997) states that “despite the urgency of the possibility of death”, it is important that professionals and family proceed to work through issues in consultation with the ill person at a pace that feels safe for all parties (p. 154). This approach suggests that, as well as in the personal sphere, a workplace (an employer and/or employees) may also be better served by applying a similar pace when working through end-of-life workplace transition issues. Altschuler (1997) states that it is through creating space for each person to gain some understanding of their own response that people become free to “redefine their connectedness, and retain agency, competence and integrity” (p. 154). Illness, according to Altschuler (1997), can be seen as “a series of disruptive events, during which all the structures and very forms of knowledge that underpin daily life are changed: the world of pain and suffering, formerly only a distant possibility, becomes a reality; where rules of reciprocity and mutual support alter, and self-worth, closely linked to being an effective or creative professional (or employee) in the world of work is challenged” (p. 132). Principle three, in *Improving Care for Older People; A Policy for Health Services* (2003), “places the person at the centre of their own care and considers the needs of the older person’s carers” (Department of Human Services, Victoria, p. 18). In essence, it appears that mutuality and a person-centred approach to support are inherent in retaining a sense of dignity and quality of life for all people, including in the workplace, where an ill employee/employed carer works.

There may also be a spiritual dimension, as Rumbold (2002) notes:

mutuality challenges some well-established assumptions about the offering of spiritual care to people who are dying and ... it recognises dying people as human beings who by their very act of dying are prophets speaking to us, not as human beings empty of value (p. 128).

When colleagues permit the ill employee or employed carer to contribute to their workplace in meaningful and realistic ways, each person’s dignity and integrity is being honoured through a spirit of mutuality. A pooled sick leave policy, such as the National Australia Bank Group has in place, embodies this concept (*Corporate Social Responsibility Report, 2004*, p. 17). Enacting flexible leave arrangements, using discretionary funds, and rearranging roles and responsibilities also embeds mutuality in meaningful ways that endorse a person-centred approach to workplace support.

A Best Practice Support Model in the workplace will require systems and processes that combine the need for flexibility whilst remaining person-centred through the transition period.

The ill employee

Some barriers to obtaining and retaining employment for an ill employee include intermittent effects of illness, the need for flexibility for taking time off, and management of illness disclosure. Further obstacles include de-skilling, shifts in life goals, ageing, and explaining an extended absence from the workforce (Grierson et al, 2002, p. 89)). Grierson (2002) also identifies five main reasons why employees ceased work: low energy levels, stress, depression or anxiety, poor health (p. 89). Half of these employees had returned to work primarily for financial reasons. Once back at work they reported difficulty in concentrating and tired more easily, resulting in working reduced hours.

The need for financial security, social contact and a sense of worth are vital factors in HIV positive people's desire to work in paid employment (Grierson et al, 2002, p. 89). Survey results from *the Work and Cancer: How cancer affects working lives* (2005) study by CancerBACUP in the UK identifies that over half (58%) of employees with cancer are keen to continue working (p. 6).

Employers may need to explore creative options with a health promoting 'palliative approach' and/or a health promoting grief/loss/bereavement/death education service to help manage an ill employee's physical and emotional limitations. An employer could continue to value an ill employee's contribution when all internal avenues and possibilities have been exhausted through, for example, re-negotiating an employment contract for a specific task - one that captures the wealth of the employee's knowledge and experience.

The employed carer

The report, *Research Findings from Studies with Companies and Caregivers* (1999), convened by Myrl Weinberg of the National Health Council USA, states that "caregivers find their end-of-life situations very difficult, stressful and devastating" (p. 32). Aoun (2004) states that "role changes within the family, lack of social support, fears of being alone... lack of control over everyday life and changes in paid employment" all contribute to caregiver stress (Palliative Care Australia, p. 16). According to Aoun "nearly 60% of carers experienced negative effects on life opportunities including paid work" and "the primary caring role appears to reduce a person's chances of being employed" (ABS, 1999 cited in *The Social Impact of Caring for Terminally Ill People in Australia, 2004*, pp. 17, 20). This literary review identified the need for "more flexible employment arrangements to reduce work conflict and give carers more options in combining paid employment and caring" (Aoun, 2004, p. 35).

Briggs and Fisher (2000) recommend that "the Australian government, unions and employer bodies develop education programs for employers and employees, and amend Awards and conditions where necessary, to make work places more carer friendly and ... carers returning to the workforce be recognised as a group of job seekers needing intensive employment assistance" (Carers Association of Australia Inc., p. 37). Russell, Browne et al. (2004) identify the value of flexible work arrangements when an employed carer needed to stay at home to care for their dying mother (p. 21). The aspect of workplace support demonstrated the recognised interdependence

between work and family responsibilities enabling the employed carer to be with her mother “at the end” (2004, p. 21). This approach allowed each person to maintain dignity throughout the experience, including the mother’s dying, death, and the carer’s early days of bereavement.

One piece of international literature identifies that “caregivers’ needs fall into three main categories: financial, emotional and practical” and states that only 25% of carers at work seek information from an Human Resource Department to help them manage their work-family responsibilities (Workplace Task Force, Directed by the National Health Council, the National Alliance for Care-giving, and the Last Acts Campaign, 1999, pp. 1, 32). This research found that “nine in ten carers speak to their supervisor or co-workers about their situations, with two thirds having spoken to both” (1999, p. 32). This suggests that the majority of managers and co-workers appear to be grappling with the employed carer issues and needs without the knowledge, support or advice of HR & OHS Departments being given directly to the carer. A preferred approach in workplaces may be the strengthening of access to: internal or external OHS/HR, management, support, information and advice about work and life-threatening/terminal illness. Consultancy to the manager and co-workers may include a workplace assessment.

Introducing the concept of, and access to, ‘palliative approach’ philosophy and practice may reduce the need for complex palliative care service provision and support further along the illness and/or carer trajectory. An appropriate strategy might include access to a *Program of Experience in the Palliative Approach* and/or grief, loss and bereavement/health promoting death education program into the provision of workplace support for life-threatening/terminal illness. *The Last Acts Workplace Taskforce* research findings established that “when supervisors reassured them that their jobs would be secure they felt relieved and grateful as a result “ (1999, p. 35). It needs to be emphasised that reassurance to employed carers about their employment status may assist them to function as competently as possible at work and also in their caring responsibilities at home.

Access to sufficient and flexible support services in the community for the ill person may influence the employed carer’s capacity to continue at work. Extending permission for a carer to take time-off even when the person they are caring for is feeling well is also an important consideration for employers to keep in mind (Charles-Edwards, 2000, p. 71).

The Princess Royal Trust for Carers, UK, in *How Do I Know if I’m a Carer*, notes that “people usually take on the responsibility of caring well before they recognise that the word ‘carer’ applies to them” (2005, p. 1). The burden of work and caring tasks and responsibilities may increase as the severity of the ill person’s symptoms increase. Employed carers may not be prepared for its impact or having to declare their carer status to their manager at work. A Best Practice Support Model will need to take into account support strategies that can assist the employed carer to cope with all the unpredictability and uncertainty inherent in carrying out the tasks of caring for

a terminally ill person including through the dying, death and bereavement trajectory.

Some of the plethora of policies and strategies identified to support employed carers of a person with a life-threatening/terminal illness are suggested in the policies, strategies and implementation section of this document.

Cessation from, and return to, work

Cessation from, and return to, work are important considerations in the development of a Best Practice Support Model for both an ill employee and employed carer. Review of these two specific areas of workplace support was considered beyond the scope of this literature report but would be worthy of further research in the future.

The colleagues

It is important to recognise the role that colleagues contribute to the provision of workplace support when there is an employee living with a life-threatening illness and/or employed carer. Some colleagues' needs have been outlined in other sections of this document. Hofsess (USA, 2002), in the newsletter *The Forum*, asserts that "how caring an employer is perceived to be after a loss can make the difference between an employee staying with or leaving a job" (The Association for Death Education and Counselling, USA, p. 1). It is beyond the scope of this report to identify barriers and strategies specifically designed to support colleagues finding themselves in this situation but these matters would be worthy of further research in the future.

Support mechanisms that might inform the model

A public health approach to palliative care, healthy grief and bereavement support and death education places a Best Practice Model in the realm of health promoting 'palliative approach' support with general medical practices taking a key role in its provision. A support model needs to reflect this approach in its framework and application.

In developing a social model of practice, health promoting palliative care, according to Kellehear (1999), recognises "the social character of health, and emphasises the importance of education and information in the achievements of health goals, and that health is everyone's responsibility" (p. 76). Kellehear argues that "the primary function of any health promoting palliative care program is to provide support – in the form of information, education, advocacy, referral and, in small groups, interpersonal support" (p. 105). This encourages interpersonal re-orientation through sharing experience, information, resources, and tasks (p. 38). A workplace may embrace such elements of support at different levels within the business including programs and services with, and for, the employer/manager. Bottomley (2001) suggests that "effective workplace support involves creating an atmosphere of emotional safety, and ... empathetic and active listening through clarifying, containing, being genuine, ethical, and respectful of difference contributes to this sense of safety" (p. 35).

Supportive relationships, Bottomley (2001) argues, require “rapport, affinity, empathy, trust, acknowledgment of and strategies for exploring ambivalence; clear, achievable, mutually agreed goals; safety, boundaries, clarity about roles, and relative calm” (p. 35). In this context non-judgmental listening, opportunities to explore conflict related to issues of power, trust, security and vulnerability, access to professional supervision, and an acknowledgment of the place of spiritual wisdom (for individual and/or group discernment) may all contribute to successfully transitioning a workplace when an employee has a life-threatening illness or is an employed carer.

Renzenbrink (2002) has identified that a Best Practice Model needs to offer, as part of grief, loss and bereavement support, policy, program infrastructure and sequencing of care (p. 5). Regular meetings between a manager and the ill employee/employed carer to plan future contingencies can contain and clarify in ways that manifest a sense of safety. Similar meetings with staff and informal conversations between a manager and other individual staff members on a regular basis may also ‘hold’ a workplace emotionally through periods of instability when a carer is bereaved.

Support, according to Charles-Edwards (2000), requires noticing and accepting how the person is at any particular moment (p. 41). House (1981), on the other hand, conceptualises support needs (for the ill person) more comprehensively:

- economic support: instrumental helpful behaviour (includes helping financially, helping colleagues to do the ill person’s work);
- emotional support (empathy, caring, love and trust);
- information support (to the person or to the organisation that helps them cope);
- appraisal support (information to facilitate self-evaluation (pp. 24, 25)).

The literature does not comprehensively outline many strategies to deal with the complexity of support needs *within* [this author’s emphasis] a work environment on a day-by-day basis where employees working alongside each other may be sharing the burden of the illness experience with the ill employee or employed carer. An internal support person may be the ‘linchpin’, with specific external support given to the role, to carry the transition through successfully. This dimension to workplace support has not been tested or researched to date and may be an important element to establish and evaluate when piloting a Model.

Policies, strategies and implementation

The Employer

As can be seen from the section: ‘Economic impact of inadequate support’ and ‘Person-centred care’, flexibility in managing work roles and leave (Grierson 2002, Last Acts Workplace Committee 1999) is crucial for business productivity and the avoidance of significant hidden costs (James and Friedman 2003). Some strategies and policies might include:

Flexi-time

- flexible working schemes that may include 'core' hours when all staff members are expected to be at work, but with the inbuilt flexibility to work the remaining contracted hours at the times best suited to the employee with a life-threatening illness or employed carer of a person with a life-threatening illness;
- exploring the possibility of flexible work arrangements e.g. working at home on some days.

Leave

- leave policies that include different types of leave to meet a range of work-family commitments with some leave available at short notice:
- staff pooling of unused sick leave (within specific criteria) for use by an ill employee or the carer of an ill person (also within specific criteria) – creating a 'sick leave' bank for employees to draw on in times of need.

Workplace adjustment

- access to use of a phone for private phone calls (in a confidential setting);
- a room set aside for appropriate short-term use by an ill person when the employed carer needs to work;
- workplace and individual employee Awards for supportive responses to a terminally ill employee and/or employed carer;
- a company charter that endorses and promotes a carer friendly workplace;
- access to future career planning and advice;
- access to workplace social activities (to keep socially connected);
- a carer 'buddy'/mentoring program;
- contact with a company's EAP, confidential welfare/financial planning service, industry HR department and/or union. These services may assist in accessing entitlements, benefits, early access to superannuation and/or life insurance, counselling and carer information.

Policy and strategy implementation

The Grief At Work Resource Manual, USA (2000) identifies thirteen policy considerations: sick leave, donation of sick leave, bereavement leave, leave without pay, flexi-time, job protection (not necessarily role protection), financial support, informing others/co-workers, calling on the family, attending the funeral, collecting personal belongings, family visits to the worksite, and helping the family with paperwork (pp 1, 2).

The following stakeholders would need to be informed of any implementation; HR departments and consultancy services, EAP programs, OHS advisors and representatives, health and well-being programs and consultants, business counselling services. These parties will all need to be aware of the range of options available when advising employers and employees negotiating regarding the healthcare, well-being, treatment and/or carer needs of the employee.

The American Hospice Foundation's *Grief At Work: A Guide for Employees and Managers* (1996) identifies specific information that may be assembled in a kit for the ill employee. This includes:

- brochures about the Medical Treatment Act, Medical Power of Attorney, Advance Directives;
- a list of local palliative care services and their contact details;
- a list of accredited funeral directors and their contact details;
- a list of airlines offering priority travel for family members of a dying person;
- suggested appropriate reading material for the ill employee and/or the employed carer;
- brochures on death education, preparation for death, and/or understanding disease processes;
- access to appropriate support groups e.g. for cancer, motor neurone disease, HIV/AIDS;
- information on relevant financial matters e.g. employment contract/award entitlements, company benefits, Centrelink financial support services, benefits and entitlements, early access to life insurance and superannuation.

It is beyond the scope of this literature report to include every policy and strategy identified in the literature reviewed. Each business would need to identify the relevant aspects of a Best Practice Support Model to suit its own workplace as end-of-life needs arise, and as part of succession planning and workplace transition planning and support. An external support/consultancy role may facilitate integration of specific elements of the Support Model into workplaces and link relevant components of the various sectors as needed.

Education and Training Needs

Comprehensive identification of education and training needs and strategies for a Best Practice Support Model for Life-threatening Illness in the Workplace is beyond the scope of this literature report. Further work needs to be undertaken in this area.

Key Messages

1. The literature search established workplace needs at an earlier stage of the illness/carer trajectory. Hence the term 'life-threatening illness' replaced the term 'terminal illness' and the parameters of the project were defined as 'from the point of diagnosis through to resolution of bereavement'.
2. There is a need to engage the Australian community and politicians in the discussion of the issue of end-of-life support in the workplace.
3. Grief gives rise to hidden financial costs to business. Comprehensive grief programs in the USA have significantly improved business productivity.

4. Humanity must coexist with meeting production needs. All employers need to be encouraged to place employees with life threatening illness (or employed carers) at the centre of their decision-making process at the employees' most vulnerable periods.
5. Mutuality and person-centred support contribute significantly to the respect and dignity of employers and employees needing end-of-life workplace support.
6. There are many barriers to an employee with life threatening illness/employed carer retaining employment. Employers may need to explore creative options that may involve re-negotiating different employment contracts, role tasks and relationships.
7. Research has shown that leaders and managers in USA, affected by the death of a loved one, are at risk of making serious errors of judgment at work. Equivalent research is yet to be undertaken in Australia.
8. Stigma and discrimination may emerge at any stage along the illness or bereavement trajectory. Stigma can be pervasive and all-consuming to a person.
9. As overly intrusive palliative support to business may give rise to stigma and discrimination, workplace support may be more appropriately provided through well-resourced and creative external support practitioners, programs or services.
10. Grief can be a taboo in the workplace, adding to potential stigma and discrimination, and needs to be considered as a workplace health and safety issue.
11. Standard Australian employment contracts with three days bereavement leave are profoundly inadequate and are based on a lack of understanding of grief and bereavement or specific needs in other cultures including the indigenous communities.
12. The burden facing an employed carer or an employee with a life threatening illness may escalate. Decisions need to be made about their needs at work, as a carer, or as an ill person undergoing treatment. These issues need to be addressed simultaneously.
13. Flexible leave arrangements may increase the commitment to work of an employee with life threatening illness (or employed carer) and, at the same time, express the employer's commitment to their employee.
14. In relation to support for employees with life threatening illness or employed carers, employers need to consider including relevant elements of support into workplace policies and procedures: information, education, advice, referral, small group support, fostering a culture of emotional safety in the workplace.

15. Keeping colleagues informed about the health status of an employee with life threatening illness is important but it inevitably relies upon disclosure. However the desirability of disclosure must be weighed up against the issue of confidentiality (and even the right to refuse support). Willingness to disclose by an ill employee or employed carer is likely to be influenced by issues of stigma and discrimination.

16. Employees with life threatening illness or employed carers of a dying person should be kept socially connected to, and within, their workplaces. Social and cultural aspects of a person's illness/carer experience in their workplace must be taken into account.

17. The transferability to the Australian situation of the leave provisions of the Canadian Employment Insurance Program is worthy of closer examination.

18. The potential exists to align a Best Practice Support Model to health promoting palliative approach, grief and bereavement, and death education concepts.

SECTION 2

Where does a Best Practice Support Model for Life-threatening/Terminal Illness in the Workplace 'fit' into Palliative Care?

Some international perspectives

The report *Work and Cancer: How cancer affects working lives* (UK, 2005) identifies that 54% of employees with cancer are “not being advised by their cancer doctor about how their treatment will affect their ability to work and are struggling to manage side effects in the workplace during and following treatment (pp. 6, 16). The 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” (p. 25). The findings in the report concluded that “a significant proportion of employees who had been diagnosed with cancer did not return to work after treatment and ... the costs of withdrawal from the labour market were substantial, in financial terms to employers and Government through loss of labour and skills, replacement costs, and sick or early-retirement pay and to employees through loss of earnings” (2005, p. 6). Important costs to the individual’s psychological well-being were also identified (2005, p. 6).

International literature and palliative care websites highlight the fact that palliative care providers and international palliative care peak bodies are developing partnerships, resources, education and training material and/or seminars with the broader HR sector, EAP programs and other key stakeholders in, or aligned to, the business sector (Irish Hospice Foundation website, *Grief at Work: Lunch and Learn Series*, Spring 2005, January, February, March, 2005; The American Hospice Foundation website, *Grief at Work Resource Manual*, Fitzgerald, 2000; and The National Hospice and Palliative Care Organisation, USA, *Caring Connections Information*, 2005). Australia has yet to determine the most appropriate approach to take to integrate palliative care into the workplace/business sector in health promoting ways.

The Australian setting

A Best Practice Support Model for the Australian workplace is being developed amidst further industrial reform at the Federal government level, and at a time when some innovations to palliative care support and care are being developed, piloted, evaluated and implemented through the *Caring Communities* projects.

The Australian National Palliative Care Strategy (2000) outlines goals to improve awareness and understanding about palliative care and to promote and support partnerships in the provision of that care (pp. 10, 21). The *Guide to Palliative Care Service Development: A population based approach* (2005) states that “palliative care and health promotion providers may work with workplaces et al. to design joint programs that increase public awareness of

topics of importance to dying people, their primary carers and families” (p. 24). This approach is seen to be a community and public health initiative in palliative care that aims to bring about changes to social settings and attitudes (Palliative Care Australia, 2005, p. 24).

In this literature report, workplaces are seen to be ‘social settings’ or ‘communities’ (refer to pp. 4,13, 14 in Section One of this report).

An example: Victoria

This section explores the situation in the State of Victoria as an example of what might also apply in other parts of Australia or the world. The model needs to reflect the local culture, circumstances and priorities if it is to be effective at the local level. In Victoria, service providers are being aligned to State government strategic directions. Regional consortia have been formed to develop business plans and are forming relationships with regional Integrated Cancer Services networks. Four statewide bereavement services have also undergone a review. It is timely for a Best Practice Support Model to be developed in line with the above changes.

Outlined in the Victorian DHS document *Strengthening Palliative Care: A Policy for Health and Community Care Providers 2004-2009*, is a public health focus on improving the health of whole populations by empowering people and communities and health promotion initiatives (Principle Seven, 2004, p. 53). These initiatives include “community education, social policies and practices, and prevention strategies” (Palliative Care Australia, 2003, cited in *Strengthening Palliative Care: A Policy for Health and Community Care Providers 2004-2009*, Dept. of Human Services, Victoria, 2004, p. 53).

A Victorian statewide bereavement review of four DHS funded Grief, Loss and Bereavement services was undertaken in 2004 (*Final Report: Review of Specific Grief & Bereavement Services*, the Nucleus Group). One recommendation in this report identified that grief, loss and bereavement services could be implemented through the community health care service system (The Nucleus Group, July 2004). The grief and bereavement review found “that most people manage grief and bereavement using *natural social supports*” and that those who did need it were accessing it through community health services, funeral services, community based palliative care, generalist health and welfare workers and private practitioners (pp. 3, 15). One of the key findings recommends that “the grief and bereavement sector should also participate more strategically in existing community capacity building initiatives” (2004, p. 3). The report also states that bereaved individuals had their basic needs met through “recognition and validation of their grief and grieving style from family, friends, *employers* [this author’s emphasis], and the general community” (2004, p. 9). Work colleagues were acknowledged in the report as people potentially impacted upon by the death of an individual (2004, p. 14).

The report argues for centering the future development of local grief and bereavement support on the community health platform (p. 16). It identifies the benefits in positioning grief and bereavement information and community education within the community health sector with planning, expert resourcing

and support provided by the specialist services (2004, p. 11). One recommendation is that education and training - as a high priority need and as a capacity building strategy - be developed and systemically delivered to counsellors and practitioners in community health services (2004, p. 22). Opportunities exist to identify innovative approaches to healthy grief and bereavement support in the workplace.

A Best Practice Support Model would recognise employees living with non-malignant life-threatening illnesses, for example Motor Neurone Disease and HIV/AIDS, and employed carers looking after these people in their homes and communities, as being part of the population served by the Support Model to be aligned to DHS and DoHA strategic directions for palliative care (*Strengthening Palliative Care: A Policy for Health and Community Care Providers 2004-2009* (2004), *National Palliative Care Strategy* (2000), and *A Guide to Palliative Care Service Development: A Population based approach* (2005).

General Medical Practitioners

The DHS document, *Strengthening Palliative Care: A Policy for Health and Community Care Providers 2004-2009*, states that General Practitioners are usually the first points of contact for people seeking primary health care (Street et al. 1999 cited from *Care: A Policy Strengthening Palliative for Health and Community Care Providers 2004-2009*, Department of Human Services, 2004, p. 46). Charles-Edwards (2000) states that “GPs can be a valuable resource in helping people work out when they are ready to return to work” when the person is bereaved (*Bereavement at Work*, UK, p. 19). General medical practitioners are considered essential to the primary care provider system and Palliative Care Australia argues that, “at an absolute minimum, all people diagnosed with a life limiting illness, require access to a primary care provider with knowledge and skills in the palliative approach” (*A Guide to Palliative Care Service Development: A population based approach*, p. 16). A Best Practice Support Model will need to explore the role of GPs in supporting workplaces when an employee has a life-threatening/terminal illness or an employed carer is supporting a dying person at home, or is bereaved and is returning to work.

Any further research in relation to medical practitioners and their role in providing workplace support in a Best Practice Support Model is beyond the scope of this literature report.

The palliative care provider

The palliative care provider, using a palliative approach, may provide advice to employers of possible strategies and policies to be implemented by managers, or HR/OHS/EAP programs. Therefore, a Best Practice Model will need to include access to the following relevant information and services:

- contact with local carer centres for advice, advocacy and information about other local services and/or a ‘needs assessment’;
- information about relevant illness and disease by specialist disease services;

- information about grief, loss and bereavement and access to 'palliative approach' support services;
- access to local hospice/palliative care services offering: counselling, information, respite carer, day hospice, transport, supplies and equipment.

A palliative approach provider may also offer:

- education and advice on appropriate treatments, medications, home modifications, diet, physical activity, OHS issues/risk management;
- access to psychological, social, emotional, spiritual, grief and loss support, and death education for the ill person/carer;
- education and training for the managers and work colleagues on death education, carer support needs, and grief, loss and bereavement issues in the workplace;
- access to pre-packaged materials on end-of-life issues (and dissemination through the workplace via HR departments and EAP programs);
- access to internal and external pastoral support supervision and support (in addition to external counselling services);
- information on self-care strategies e.g. time-out for self, health promoting activities;
- access, with the employee's permission, to medical information from medical practitioners to assist the employee and management in workplace (role, task, employment) decision-making;
- assistance in the development of appropriate workplace policies and strategies when an employee is experiencing end-of-life transition.

The DHS *Guide to Developing your Regional Palliative Care Plan* (2004) signals an opportunity for "new ways of working together" (p. 1). This document highlights the possibility of creating links with "new initiatives e.g. Integrated Cancer Services Program and Primary Care Partnerships and encourages regional palliative care plans to strengthen DHS palliative care policy principles" (2004, pp, 1, 3). Policy principle three is for "people with a life-threatening illness and their carers and families to have care that is underpinned by the palliative approach" (2004, p. 3).

Whereas palliative care service provision is generally seen to be applicable to the later phases of terminal illness, Palliative Care Australia (2005) aligns best practice palliative approach support at an earlier stage in the illness trajectory (Standards for Providing Quality Palliative Care for All Australians, p. 11). In this context 'health promoting palliative approach' support may be a more appropriate palliative care response to end-of-life workplace support.

A support model may need to consider the possible sites from which palliative approach support and consultancy/death education might be delivered for ease of access by business. For example, general medical practices, community health centres, employer bodies, business counselling and advice centres. The model may need to address creatively any sensitivity to death, dying or palliative care.

The proposed Support Model is to be tested and evaluated as part of the project brief. This process may further assist in refining our understanding of the best 'fit' that health promoting palliative support (includes death education) can bring to Australian workplaces, to employers/managers, colleagues, and the ill employees and/or employed carers and families served by the palliative care sector.

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Walter T. (1999) *On bereavement: The culture of grief.* Buckingham: Open University Press.

Weinberg M. (1999) (1) *Workplace Task Force Research Findings from Studies with Companies and Caregivers, Workplace Task Force of the Last Acts Campaign*, (2) *Workplace Committee of the Last Acts campaign, Workplace Taskforce Research Findings from Studies with Companies and Caregivers.*

DATABASES, SEARCH ENGINES, LIBRARIES

- ADEC (Association for Death Education and Counselling, USA)
www.adec.org
- American Hospice Foundation
www.americanhospice.org
- Access Information at Alfred Hospital
- Australian Bureau of Statistics
- Australian Institute of Family Studies Library
- Australian Resource Centre for Sex, Health and Society (ARCSHaS)
Latrobe University,
- Brain Foundation of Victoria
www.brainfoundation.org.au
- CancerNet
- Carers Association Victoria Inc. Victoria Library
www.careersvic.org.au
- Caritas Christi Library, Kew
- Centre for Grief Education Library
You might like to visit the Centre for Grief Education library and have a look at the resources available. This is a closed reference library however there is a facility to photocopy materials of interest.
www.grief.org.au
- Clinicians Health Channel
- Creative Ministries Network (formally Urban Ministries Network)
www.cmn.unitingcare.org.au
- Deakin University Library
- Emonet Resource Net: University of Queensland: Emotion in the Workplace.
- Google.com
- Irish Hospice Foundation
www.hospice-foundation.ie

- NALAG (National Association for Loss & Grief) Victoria Library.
- National Breast Cancer Centre
www.nbcc.org.au
- National Library of Australia
 - 1) Australian Libraries Gateway
www.nla.gov.au/apps/libraries
 - 2) National Library's Catalogue
[www/nla/gov.au/catalogue](http://www.nla.gov.au/catalogue)
 - 3) Document Supply Service
www.nla.gov.au/dss/index
 - 4) Journal Articles
www.nla.gov.at/pathways/jnls/newsite
- Peter MacCallum Clinic (cancer) Central Cancer Library
www.petermac.org
- The National Hospice and Palliative Care Organisation
www.nhpc.org
- Victorian Aids Council Library
www.vicaids.asn.au
- University of Wollongong Library
www.uow.edu.au

GLOSSARY AND KEY TO ACRONYMS

1. Bereavement

A “broad term that encompasses the entire experience of family member and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one’ (Christ, Bonanno, Malkinson & Rubin 2003, p554)

2. Business Sizes:

The following groups are identified:

- Micro

Micro businesses are those businesses employing between 1-4 people.

- Small

Small business (excluding Agriculture) are those businesses employing between 5-19 people (2004, ABS).

- Medium

Medium business are those businesses employing 21 to 99 people inclusive (by default of the ABS definitions of small and large businesses).

- Large

Large business are those businesses employing 100-199 people.

(www.abs.gov.au/ausstats/abs)

3. Caregiver/carer

The caregiver is generally in the close kin network of the patient and is usually self identified e.g. spouse, partner, adult child, parent or friend. This person undertakes to provide for the needs of the patient and may take on additional tasks of a technical nature to provide ongoing care for the patient, e.g. administration of medications (Standards for Providing Quality Palliative Care for All Australians, May 2005, p11)

At the same time, carers want help for their practical needs, such as financial advice, home care and respite, and access to information specific to their needs; support to discuss their concerns and feelings and knowledge that the best possible care and advice is being provided. (National Health Priority Action Council 2004)

4. Death Education

The simple aim of any death education program is to encourage people to learn what they need to know about death and dying. (Health Promoting Palliative Care, Allan Kellehear, 1999 p79).

Death Education can serve similar functions to the usual health educational programs: providing a forum for the dissemination and discussion of death-related issues – such as social preparations for death, philosophical, existential or religious (that is, spiritual) discussions about death, or information and education about grief and loss. (Health Promoting Palliative Care, Allan Kellehear, 1999 p2).

5. Grief

“refers to the person’s response and reactions to the loss” (Martin and Doka, 2000 p14)

“a reaction to loss... the psychic energy that results from tension created by and individuals strong desire to:

- a) maintain his or her assumptive world as it was before the loss
- b) accommodate themselves to a newly emerging reality resulting from his or her loss,
- c) incorporate this new reality into an emerging assumptive world’

(Martin and Doka, 2000 p15)

6. Life-threatening

Life threatening means the disease is capable of ending life but time is uncertain. (Social work theory and practice with the terminally ill. JK Parry 1989 p22)

7. Life-threatening illness

Life-threatening illness is a medical diagnosis for diseases that may cause death. This does not mean that the death is imminent or inevitable. However both the diagnosis and the disease may cause physical, psychological, emotional and spiritual changes for the ill person, their friends, managers and work colleagues.

These changes may cause diverse economic, information, emotional and appraisal support needs for each party in the workplace. (Workplace Support Model Reference Group 2004)

8. Loss

“ being deprived of or ceasing to have something that one formerly possessed or to which one was attached (Martin & Doka, 2000, p12)

9. Palliative Approach

A palliative approach is an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in provision physical, psychological, social, and spiritual care. Application of the palliative approach to the care of an individual patient is not delayed until the end stages of their illness. Instead, it provides a focus on active comfort-focused care and a positive approach to reducing suffering and promoting understanding of loss and bereavement in the wider community. Underlying the philosophy of a palliative approach is the view that death, dying and bereavement are all an integral part of life (Standards for Providing Quality Palliative Care for All Australians, May 2005, p11).

The palliative approach that improves the quality of life of patients facing life-threatening illness and their families is becoming increasingly important. This approach improves quality of life by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement (adapted from World Health Organisation 2004a, Strengthening Palliative Care: a policy for health and community care providers 2004-09, October 2004)

10. Palliative Care

Palliative care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life.

The World Health Organisation describes palliative care as: "...an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications." (Standards for Providing Quality Palliative Care for all Australians, May 2005, p10)

11. Specialist Palliative Care Provider

Specialist palliative care provider is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available) who provides consultative or ongoing care for patients with a life limiting illness, and support for their caregiver/s and family. Specialist palliative care builds on the palliative approach adopted by primary care providers, and reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers work in two key ways: first by providing direct care to reflect individuals and their families, and second by providing a consultancy service to primary care providers and therefore supporting their care of the patient and family (Standards for Providing Quality Palliative Care for all Australians, May 2005, p12).

12. Stigma

Components of stigma include when: (Link and Phelan 2001, p367)

- People distinguish and label human differences.
- Dominant cultural beliefs link labelled persons to undesirable characteristics - to negative stereotypes.
- Labelled persons are placed in distinct categories so as to accomplish some degree separation of 'us' and 'them'.
- Labelled persons experience status loss and discrimination that lead to unequal outcomes.
- Stigmatisation is entirely contingent on access to social, economic and political power that allows the identification of 'differentness', the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion and discrimination.

13. Terminal Illness

When cure and remission are beyond the capacity of current medical treatment (Terminal and Life Threatening Illness and Occupational Perspective. KD Tigges and WM Marcil, 1988, p227)

AIG: Australian Industry Group

CALD: Culturally and Linguistically Diverse

DHS: Department of Human Services

DoHA: Department of Health and Ageing

EAP: Employee Assistant Program

HCV: Hepatitis C Virus

HIV: Human Immunodeficiency Virus

HR: Human Resources

OHS: Occupational Health and Safety

PEPA: Program of Experience in Palliative Approach

PMF: Patient Management Framework

RICS: Regional Integrated Cancer Services

VECCI: Victorian Employers' Chamber of Commerce and Industry

