A Best Practice Support Model for Life-threatening Illness in the Workplace

Final Report

A project funded

under

The Caring Communities Program

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Executive Summary

A *Caring Communities* project, auspiced by Palliative Care Victoria in partnership with Creative Ministries Network, and funded by the Australian Government Department of Health and Ageing, has developed a Best Practice Support Model for Life-threatening/Terminal Illness in the Workplace over a 2.5 year period.

The aims of the project were to work with employers and employees on the development of policies and strategies to develop a model of best practice support for employees, their families, employers and work colleagues to cope with the changing situation as disease progresses. The scope of, and participants in, the project included employers/managers, work colleagues, ill employees from diagnosis through to their death and employed carers from disclosure of carer status through to resolution of their bereavement in small, medium and large businesses.

The project is considered by leaders in the palliative care sector at local, national and international levels to be pioneering work for the palliative care sector, and the Literature and Research Reports to be seminal works. The success of the project centred on the importance of critical conversations through 'vital listening' and relationship management skills. Different use of terminology, depending on the target audience, was also a significant factor that influenced its success.

The project generated a Literature Report, a Research Report, a six-step Best Practice Support Model for Life-threatening Illness in the Workplace, and a range of resources for the workplace.

Workplaces were enlisted to assist in researching the existing framework legislation, awards, policies and strategies that support the workplace and people with a life-threatening illness and their carers who may still be working. 100% return rate of signed interview schedules was achieved for the university ethics approved research.

The background and context

The project arose from an awareness that many people who are faced with life-threatening/terminal illness have a diminished capacity to continue in the workplace. Their own life-threatening/terminal illness or that of a close family member creates emotional and financial pressures that can impact on family well-being, work productivity and occupational health and safety, sometimes resulting in dangerous situations. Developing a Best Practice Support Model for Life-threatening/Terminal Illness in the Workplace was seen to be an effective way to assist employers when dealing with, and managing, life-threatening illness/carer responsibilities in their workplace.

The project sat within a health promoting model of palliative care and was seen to be a public health initiative as per *Palliative Care Service Provision in Australia: A Planning Guide* (Palliative Care Australia, 2003, p 13). The final evaluation report stated that the model developed by the project recognised the workplace, an important community site, as an appropriate point of dissemination for the 'palliative approach'.

The literature report

The report identified that:

- the word 'terminal ' (Illness) was not appropriate;
- a formal Best Practice Support Model for Terminal/Life-threatening Illness in the Workplace did not exist in Australia;
- a variety of human resource management policies and strategies had been developed and implemented overseas to provide end-of-life workplace support;
- occupational health and safety polices and strategies to provide appropriate grief, loss and bereavement support at work did not exist; and
- workplace support did not include support for employers/managers.

The literature report also established that:

- current Australian legislation does not cater for end-of-life workplace support needs;
- the introduction of legislation into Australia, as per the Canadian Employment Insurance Act, would ensure that employed carers, within specific criteria and timeframes, could assist the employed carer to support a dying person at home without loss of employment and with income support through the Compassionate Care Benefit and
- the Victorian Workcover Authority 'The Return to Work Guide for Victorian Employers' (2005) fails to mention life-threatening illness, loss, grief, and bereavement in its report.

This information provided useful background knowledge for the project to undertake research into existing Australian workplace support issues and needs.

The research

The research found that work in Australian society is an important source of self identity for people, in two main ways:

- Work enables people to be independent and self-reliant, overcoming all that binds and inhibits them.
- Work enables people to be self-centring and self-integrating, determining for themselves whom they will be.

The research also revealed that if work is valued as an important foundation for identity, worth and belonging, the experience of illness is feared as the opposite, that is, illness is feared for loss of identity, worth and belonging. Those interviewed were fearful of four aspects about being ill:

- that life would be restricted:
- that the ill person would become socially isolated as social networks break down;
- that the ill person may suffer loss of identity when their view of themselves is discredited; either in interactions with others or from un-met expectations of their own;
- that the ill person fears becoming a burden and being more dependent.

The illness can become the major source of identity.

Three issues emerged from the stories told by the interviewees, for whom the story telling seemed to assist in creating meaning in the midst of the confusion of living with a life-threatening illness:

- assessing what support is on hand, and what is needed;
- meeting the real needs;
- four key elements of support:
  - economic support:- instrumental behaviour that directly helps the person or organisation;
  - emotional support:- the person or organisation is provided with empathy, caring, love and trust;
  - information support:- providing, to the person or organisation, information that helps them cope with the situation. It helps them help themselves;
  - appraisal support:- the person or organisation is given information or feedback to facilitate self-evaluation.

A Best Practice Support Model was developed from these insights and incorporates six steps: *critical conversations, *workplace assessment, *policy and procedure, *identification and access to resources, *training and *consultancy advice, and support via a Health and Safety Workplace (Life-threatening illness) Consultancy role that also includes support for an employer, an employed carer, and work colleagues across the illness and bereavement trajectory.

The Final Evaluation Report (Paul, 2005) established that a Health and Safety Workplace (Life-threatening Illness) Consultant role was essential in order to implement any of the six steps in the Support Model.

Integrating palliative care into the Workplace

A consultation process with twenty-two Victorian palliative care providers determined how to integrate the support model into the Australian workplace and identified education and training, and funding and resource needs and options as part of that process. Key findings were as follows:

- Businesses/workplaces, palliative care, General Medical Practitioners and the wider community need education in the support model and the provision of appropriate support; in particular, support to employers.
- Education in grief, loss and bereavement into business/workplaces, Employee Assistance programs, accountants, business counsellors, and financial advisors is necessary.
- Grief and loss support needs to be offered through information and workplace education and training.
- Businesses could formalise an internal workplace support role, with the provision of an appropriately skilled external support role available on an 'as needs' basis; also offering regular follow-up if required.
- Two distinct arms to the Support model need to be developed – one for the ill employee and the other for the employed carer.
- Two distinct arms to the Support model – one for the ill employee and the other for the employed carer.
- Awareness-raising and implementation of the Model into the business world would require specific palliative care time, funding and resources dedicated to this task in addition to education and training of the palliative care sector in the Model itself, and its implementation into business.

- Palliative care providers acknowledge the need to support the ill employee, employed carer, and work colleagues.
- Palliative care providers identified health promoting palliative approach as the philosophy and practice within which palliative support can be offered into the workplace.
- Palliative care providers identified health promoting palliative care (HPPC) as a potential framework within which to locate the Support model.
- Occupational Health and Safety knowledge is new to palliative care.
- The Health and Safety Workplace (life-threatening illness) practitioner role would need to have health promoting palliative care, community development, pastoral care, grief, loss, bereavement and death education knowledge to be able to manage the linking and support work involved in the Support Model.
- The Health and Safety Workplace (life-threatening illness) Consultancy role, in addition to the above, would need to have knowledge in basic OHS/HR/policy and management areas.
- The time, skill development, monitoring, evaluation and effort required to undertake this new initiative would need to be factored into any funding and resource allocation across each region and by each service provider over and above any specific or resource allocation to meet gaps in existing client needs.
- A bereavement care plan needs to be developed between HPPC practitioners and workplaces/a designated internal support person.
- Suggested sources of funding for the model are *fee-for-service, *government (e.g. Dept of Human Services, Commonwealth Rehabilitation Services), *business;
- The regions/each agency in Victoria could implement the model to varying degrees with appropriate education, training, supervision, and mentoring, advice, support, and consultancy in its implementation and ongoing development.