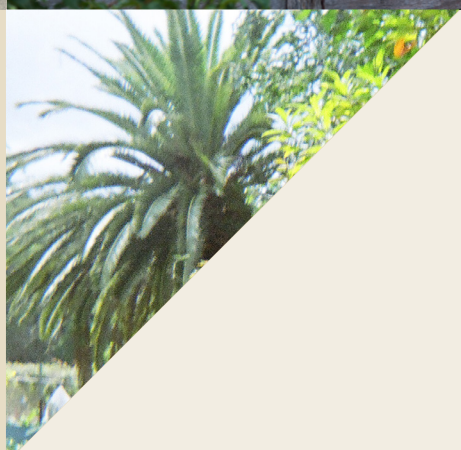# End of Life
at home

CO-CREATING AN ECOLOGY OF CARE

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Acknowledgements

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Carol and other piglets

My social networks were incredibly strong, incredibly supportive, and in many cases very intimate, both for me and for Thomas. He was a very private man so having people come and be a part of his care – he was absolutely fabulous about it – but I know it would have been hard for him. Most of these people were well known to us before all of this happened and the relationships strengthened and deepened.

People were there and were so willing to give up time and part of themselves to this dying process. They were amazing. Thomas approached death as a journey. He used to talk about going through the door – "I'm going through the door". That made it so much easier for me that we were in this together. It was a bit like when you help somebody have a baby – like attending someone on that kind of journey – down to the rubbing of the back! We didn't have huge anger or railing about it. There was very definite acceptance.

One of the most important social networks was the meditation group I belong to. We had been meeting once a month for eight years – all quite different women. We'd have a meditation, somebody would do a talk then we'd have a meal, share a bottle of wine. When Thomas got sick we kept on meeting – but with intentionality – in support of Thomas, and of me. They always brought food – the ubiquitous soup and casserole!

We knew how sick Thomas was but we had this completely unrealistic idea that, once he got to the country, he'd be okay. Looking back, we both believed it. When we moved here it became clear things were not going to work – the second lot of chemo wasn't working. I said to him, "I don't care what happens. You should stay in Sydney". We'd kept the unit and so I started moving between Sydney and going every second weekend up country for my work. I never, ever, had to go alone. Somebody always came with me and Thomas was never left alone.

All these amazing people! Thomas' GP, Marcus – he loved Thomas very deeply. It was a very special relationship. At the end of the day – every day – Marcus would call in on the way home to see him and ask, "Is there anything you two need, are you OK?" He would pat my shoulder, let me cry, say, "F…" quite a few times. He cried as well – a lovely, lovely man. Just brilliant.

Thomas' daughter, Helen, was deeply distressed about what was happening to her dad. She would come up when I was away. It was very special for him. She was a diplomat and had spent quite a bit of time overseas – a very thoughtful, insightful woman. He was very proud of her. She was hugely supportive of me – and another one who cooked! Thomas used to say, "Go out and have a coffee", and I would say, "I can do that when you're gone!" We'd laugh, but a couple of times Helen said, "Right, Janie, we're going for a walk" She was good like that. The world shrank to that bedroom, that room – that small place. I really didn't want to leave.

Thomas was not a dropper-inner type of person but he had a wide circle of people from St James where we both attended church, he had retained a lot of his friendships from there – people who cared about him came.

Oh – and of course Piglet! Now there is an example of Thomas' and my humour, but also my best friend Carol's. Years and years ago we started this Pooh Bear thing – I was Tigger and she was Piglet. We still do it. She would send emails, 'Dear Tigs', 'Dear Piglet' – 'cos she was the very shy animal and I was the very bouncy animal. Carol is my dearest, dearest friend and she was fantastic. She'd ring up or send silly emails or come over – it was an emotional support more than anything else. Thomas was Owl in this little menagerie world – and Thomas thought the world of Carol. So she was one of the few people who could pop in, apart from the church crowd. She and Marcus were the two.

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'Dear Tigs', 'Dear Piglet' – 'cos she was the very shy animal and I was the very bouncy animal.

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End of Life at home: the caring network view

The majority of people (70–80%) when asked where they would prefer to die say they want to die in the comfort and intimacy of their own homes (Gomes et al., 2013; Palliative Care Australia, 2011). However, only 16–20% of people manage to fulfil this wish.

This report documents Stages 2–4 of the *Caring at End of Life Study*, which identified the end-of-life care arrangements that allowed 20% of terminally ill people to be cared for at home. We wanted to know how ordinary people supported each other to care for someone dying at home, how their wider community supported the carer, what formal support was available to carers and how those formal and informal networks interacted with each other.

Over 200 primary carers, and members of formal and informal caring networks contributed to the study. They participated in individual carer interviews and focus groups in eight urban and regional locations. We used participatory visual methods, such as photo/voice and network mapping, to capture collaborative caring stories and illuminate the space of the possible found within communities undertaking end of life care.

Findings from Stage 1 show that formal providers are supportive of the informal networks' role in the care of the dying at home.[1] However, formal service providers do little to establish, support, or maintain the informal networks although there is much goodwill and scope for them to do so.

We identified several barriers to formal and informal networks working together more effectively. In particular, we found that the Australian policy of health promoting palliative care (HPPC) is not substantially translating to practice, and there is potential for a stronger and more proactive reorientation towards HPPC and a community capacity building approach.

The findings from this stage of the research have already been published: Horsfall, D., Leonard, R., Noonan, K. & Rosenberg, J.P. (2013) Working together-apart: What role do formal palliative support networks play in establishing, supporting and maintaining informal caring networks for people dying at home? Progress in Palliative Care. 21(6), 331-336.

Overall findings

We found that the dying person and their caring networks exist within a complex web of social-environmental relationships where the knowledge, skills, values, attitudes and beliefs of network members are influenced by the following factors:

- existing relationships with people and place
- formal and informal organisations and groups to which they already belong
- the nature of the communities in which they live
- social norms and expectations of the groups and cultures with which they identify
- experiences and knowledge of health services and other social support organisations (see also Huang, 2014).

While this web of pre-existing relationships affects a network's ability to come together in the first place we also found that this was a two way street. Members of networks who cared were affected by their caring individually, collectively and communally. No-one, and no environment, remained the same, so this web of relationships and the knowledge, skills, values, attitudes and beliefs within the web also changed. This ecological view of caring asks that we put our understanding of these interrelationships first and foremost (Richard et al, 2011).

The concept of an 'ecology of care' (as both a goal and a possibility) puts place and environment – and people's attachment to place – centre stage in end-of-life care, incorporating as it does, concepts of trust, shared norms, collective action and social agency as integral to the building of strong community-based care networks. The ecological viewpoint – that all living things have a relationship to each other and to what's around them, and that human beings (and human systems) have the capacity to act selectively with the environment to achieve a harmonious relationship (Bronfenbrenner, 1989), has very practical application in the context of an end-of-life care environment.

80% say they want to die in the comfort and intimacy of their own homes, yet only 20% do so. What can we learn from the 20% who succeed.

Findings

1

Caregivers are able to provide in-home care for someone who is dying even if they have no prior knowledge or special skill set. Research participants demonstrated that they could learn complex physical and emotional end-of-life caring skills. Carers, almost without exception, reported that they would care for the dying at home again in preference to an institutional setting.

2

A caring network maximises the wellbeing benefits of caring. These networks are essential, competent and capable of a variety of roles. They are made up of inner and outer relationships. Informal networks were strengthened and relationships deepened through the shared experience of caring for a dying person in the home. Our research identified an effective network as having the following features:

- At least one person with prior experience of death, but not necessarily home death.

- Can be any size, although in this research the range was 4–39, with the average number being 16.

- Comprise family, friends, neighbours, work colleagues. While the main carer is predominantly a family member, friends are central and consistent.

- Service providers, while essential, are seen as part of the 'outer network'. Other outer network members include employers, people who work in local businesses, schools, churches, clubs and community groups.

- Can develop spontaneously or be initiated. However, it's usually the primary carer who does most of the negotiating and organising of the network. We found no evidence that service providers *initiated* caring networks.

- Most likely to exist when either the carer or the dying person (or both) is part of a community, regardless of urban, regional or rural locations.

3

One result of participating in a planned home death is the development of death literacy. Home death, in the context of this research, is a community event where each person in the network is valued and has a role to play.

There was some evidence of wider communities becoming 'compassionate communities' whereby retailers, schools, employers, churches and local clubs became part of caring networks. However, this was not widespread and the results suggest there is scope to increase community support.

4

The relationships between the carers and the formal service providers could be weakened or disrupted by poor or inappropriate services, or insensitivity of the service providers. Lack of support from service providers for care at home could worsen the psychological impact of a terminal diagnosis.

5

Formal service providers were, by and large, greatly appreciated, especially when they were seen as going beyond the requirements of the work to assist the carer or dying person. However, they were identified as marginal to the caring network (and in some cases not mentioned at all). Thus the divide between formal and informal networks identified in the study of service providers (Stage 1) was replicated from the perspective of the informal networks.

6

Using participatory visual methods and network mapping during focus groups and interviews to carefully and sensitively document people's experiences in caring at end of life enabled us to focus on the voices of the carers and the caring networks whilst also answering our research questions.

The home is where caring communities can learn about dying and death. Here, it is a community event where each person has a role to play.

Recommendations

1

Maintaining a strong personal identity and sense of belonging, as people, is central to wellbeing for both carers and the person being cared for. The role of place is crucial to maintaining identity. It is essential in end-of-life care that we support relationships that nurture identity and belonging. This is best achieved in environments where people feel most comfortable and familiar – usually the home.

▼ We recommend that the health system and service providers give primacy to peoples' choices about preferred place of death and dying and that services and resources be mobilised to support that choice.

2

Public health policies about end of life and palliative care currently emphasise that care for dying is centred on the patient, their carer, family and the community. Our research looked at how service providers connect and/or normalise the existence and role of informal networks. We found little or no evidence that public health policy is being translated into practice.

▼ We recommend that care strategies be collaboratively developed to operationalise health promoting palliative care policies.

3

Health service practice needs to be reoriented from a predominantly protective and paternalistic model of care provision to one where the provision of various types of care is negotiated between providers and informal carers. The underlying premise is that caring networks have a range of competencies. The role of the service provider, then, is to understand those existing competencies and supplement them with their own practice wisdom and resources.

▼ We recommend that service providers activate access to the full range of relevant services and supports responsive to and recognising caring networks' existing competencies.

4

Socially-based interventions using a network approach have been successfully piloted in the United Kingdom and Ireland.

> We recommend the trial of interventions using socially based network approaches, appropriate to the Australian context, with monitoring through research of both community and health system perspectives.

5

Current models of service provision do not offer continuity of care after death. Bereavement support is largely unfunded and therefore difficult for services to provide equitably.

> We recommend that services pay added attention to the transition phase by providing written information about the role that they have after death, about the nature of grief, and resources available on bereavement support.

6

Re-orienting palliative care services to a Health Promoting Palliative Care (HPPC) framework requires transformation in care practices and cultures (Rosenberg, 2007). Practice development is a systematic set of activities underpinned by rigorous facilitation processes including: action learning; critical companionship; practice development workshops; and problem-based learning. Its core concepts place equal value on client and community experiences; local context; clinical experience; and research evidence. The integration and interrogation of these four forms of evidence is essential for change to occur. Outcomes of practice development can be described in terms of changes in both organisational and practice culture including behaviours, values and beliefs of staff involved (McCormack et al., 2014; Parlour & McCormack, 2011; Manley, 2004).

> We recommend implementing the principles and processes of practice development for HPCC consistent with international developments in evidence-based practice.

Key findings and research themes

> I'd come from the hospital setting. Working here made me a little better at working with families. It helped me learn that working with the family – how good the process can be. How manageable it can be. The experience here allowed me to do a better job working with those daughters who looked after their father at home.
>
> *Focus group member, regional*

Theme one: Networks

People's choice of place of death (in this case the home) focuses attention on informal carers and their support networks. Networks are complex entities that come together in a myriad of ways. What do they need to support someone to die at home? Support networks for carers, comprising service providers (formal networks) and friends, family, colleagues and neighbours (informal networks), have a crucial role in effecting positive outcomes for the dying person and carers (Hudson, 2003; Horsfall et al., 2012; Leonard et al., 2013).

What is more difficult to measure is the positive effect that caring networks may also have on communities – the ripples spreading out from the networks that form around an individual carer, coupled with the longer term strengthening and developing of community that might emerge from the shared caring journey.

Theme two: Service providers and service networks

The ways in which formal and informal carer networks develop and intersect, and how they undertake the collective task of caring, provides valuable insights into key sources of tension and how these relationships might be better facilitated. Issues which influenced whether formal carers could become successfully integrated into the caring network included the distinction often made between 'care as service provision'; expectations of professionalism; and 'care as relationship building' – with the latter being necessary for the creation of social networks (Horsfall et al., 2012).

The concept of care purely as service provision holds within it the danger of alienation from the kinds of human interaction and collective processes that sustain individuals and communities confronting life's final journey.

Theme three: Death literacy

In this research we also found that carers and their networks were engaged in a critical learning process to develop the knowledge and skills required to care for a person to die at home. The result is what we call death literacy. People and communities with high levels of death literacy have context specific knowledge about death and dying and the ability to put that knowledge into practice as a form of social action. Once this happens death literacy becomes a resource that people can use for the benefit of themselves, their networks and their communities, when facing the complexities of making decisions about their own care and care for others. Death literacy is 'practice wisdom', which anyone can develop.

Theme four: Social capital and community

People are already part of their community – through work, encountering one another in the street, out shopping, or as active members of groups and organisations. The data shows that carers and members of caring networks know the importance of relationship – of giving and receiving – and providing support to others. Simply by their proximity to one another, or through their chosen affiliations, people have been through life's ups and downs together. Social capital has been built through these every day experiences and activities that is accessed in varying degrees by carers, depending on the level of connection with their neighbourhoods and networks. Support comes in many forms. A strong theme is the extent to which employers and workplaces have stepped up to support carers and terminally ill workers through flexible work hours, working from home, and through caring colleagues and bosses who often provided practical help around the home as well as support at work. Faith communities are strongly (though not universally) present for carers of faith, providing practical, emotional and spiritual support. Schools and clubs play a part, as do groups who share hobbies and regular social activities where people are visible and known.

Theme five: Place

It is not a surprise that a strong connection to place should emerge as an overarching theme. A sense of belonging and social connection, the proximity of familiar objects, people and places, maintaining links with family and community, the very particular quality and identity of a home and neighbourhood, were mentioned again and again as powerfully defining aspects influencing the journey of dying at home.

People found that these factors were irreplaceable positives in their lives and impossible to recreate in a medicalised setting however personalised, or patient and family-focused a care facility might be.

Notes on style

Martha Nussbaum has suggested that the way in which we write, its form, should be considered as inseparable from its theoretical and discursive content (Nussbaum, 1990, p.3). The narratives that have been constructed here from interview transcripts, the images created and chosen for inclusion in this research text are more than just illustrations of a point. How we have written is, in itself, an integral part of the search for and statement of meaning (Yardley, 2008). The narratives, photographs and maps included in this report have moved beyond their origins as raw data illustrating the issues that surround care for the dying. They have provided a structure and context for our analysis across all data sets, inclusive of the carer's voice about their direct experiences – a vital addition to our analytical toolbox and to the interpretation of collective caring pathways.

Background
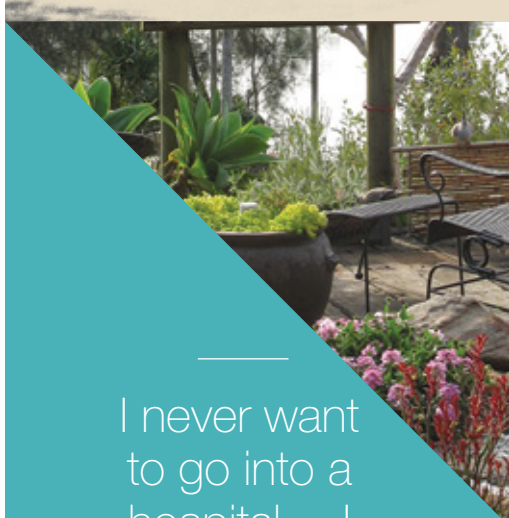
This project was born out of a concern for social justice. Research shows that of the approximately 140,000 people who die in Australia each year, about 80% want to die at home if they have a progressive, incurable illness, but only 16% –20% do so, with the majority of people dying in hospitals – often in intensive care units (Palliative Care Australia, 2011).

In Australia, most deaths (72%) are expected, and up to 90% of people with a terminal illness spend most of the final year of life at home (Palliative Care Australia, 2005). The average length of community-based palliative care is 119 days of which 117 days of care are typically provided by family, friends, neighbours and community members (Rumbold, 2010). Clearly people do most of their dying at home, yet do not actually die there.

That most people do not experience death in the place of their choice is evidence of our failing as a society at a time of life that occurs for all of us. Research, policy and service provision in Australia are not yet meeting the stated needs and desires of the majority of people. It is important that death at home becomes a real choice for people and that people and services understand what is necessary for this to be done, and done well. That is why we frame this research in the context of social justice.

The medicalisation of death and dying

Dying was once considered a social and community event. However, over the last 50 years or so, dying and death have become medicalised life events, especially in developed countries (Howarth, 2007; Kellehear, 2007). This change has profoundly altered people's experiences of death, their place of death, and greatly influenced societal attitudes about death, dying, and the provision of end-of-life care.

_____

I never want to go into a hospital… I want to be at home. I want to be around my family and loved friends… and be able to see everything that's familiar.

Focus group participant

_____

Dying has become firmly located within health care systems, with the result that, for most people, the process of dying is medicalised, individualised and institutionalised (Howarth, 2007). Community knowledge of, and skills in, end- of-life care have waned as a result of this dominance by health systems.

Today the navigation of death and dying has become the province of 'the expert' in a paternalistic relationship with the dying person and their carer/s, usually in an institutional setting (Gomes & Higginson, 2006; Kellehear, 1999). This medicalised response is beginning to be seen as incomplete (Byock, Norris, Curtis, & Patrick, 2001) and the place of the whole community in supporting its dying members, in their place of choice, is being reconsidered as an integral part of a more complete social approach to end-of-life care.

This social approach returns responsibility for care to whole communities, rather than solely health services, or dying persons and their carers, in isolation from the communities in which they live.

Health Promoting Palliative Care

Health Promoting Palliative Care (HPPC) advocates the social approach to caring at end of life, with a focus on social change (Rosenberg, 2011), through developing strategies which:

- provide education and information for health, death and dying
- provide social support at both personal and community levels
- encourage interpersonal reorientation
- encourage reorientation of palliative care services
- combat death-denying health policies and attitudes
  (Kellehear 1999, p. 19–20).

As a national peak body, Palliative Care Australia [PCA] has articulated the health promoting component of palliative care in its National Standards for Providing Quality Palliative Care for All Australians, stating that community capacity is created through partnerships between services, the dying person, their carers and family (Palliative Care Australia, 2005). This approach has found its way into the national agenda for health and wellbeing in the *Australian Government National Strategic Plan for Palliative Care* (Commonwealth of Australia, 2010) and is beginning to impact the medicalisation of death and dying. However, what is still lacking is the commitment to the community level.

The social approach, and the issue of choice of place of death, does begin to focus our attention on informal carers and their support networks. What is it that they need to support someone to die in the place of choice?

Go and find your local government area and go and find the aged care person, the person who deals with disabilities. You may think that they're not related but they are extraordinary people who have got a wealth of knowledge and they'll know who to put you on to'. So we got on to Palliative Care. They gave us a lot of equipment then they started sending the nurses in. Then the doctors came, but really, what I learnt is that we were able to do it all ourselves.

Carer 6, urban 1

Caring in place at end of life

To date our primary understandings of the experiences of caring at end of life have a narrow focus on the primary carer and the burden of care. This focus reflects a medicalised, individualized and service provision orientation (Sadler & McKevitt, 2013). The emotional, physical and psychological costs of such care are well documented (Grande et al., 2009; Zapart, Kenny, Hall, Servic, & Wiley, 2007; Australian Bureau of Statistics, 2012; Access Economics, 2010) and can include: stress, poor mental health, sleep disruption, fatigue, family and social isolation. Indeed, this is part of the experience of caring, but only a part.

It is also becoming recognised that caring can provide personal rewards as well as burdens (Zapart et al., 2007). Carers report considerable satisfaction and benefits from caring for terminally ill people. Currow et al, (2011) found that 75% of people who have cared for someone who is dying said they would do it again. Positive aspects of caring at end of life include an increase in personal satisfaction and commitment (Donnelly, Michael & Donnelly, 2006), and caring as an expression of love and increased intimacy (Aranda & Hayman-White, 2001; Horsfall et al, 2013).

It is also becoming clear that support networks for carers, comprising service providers (formal networks) and friends, family, colleagues, neighbours (informal networks) have a crucial role in effecting positive outcomes for the dying person and carers (Hudson, 2003; Horsfall et al., 2012; Leonard et al, 2014).

What is less evident is that caring networks may also have a positive effect for communities.

Social capital and community development

Refocusing on the community rather than just the individual at the end of life can contribute to greater community self-sufficiency and sustainability within the context of our rapidly ageing society and highly medicalised dying (Kellehear, 2005; Leonard, Horsfall, & Noonan, 2013; Rosenberg & Yates, 2010).

Social capital and community development are two theoretical frameworks that provide a link between the networks around an individual carer and the building and strengthening of community. When we talk of social capital we use Putnam's definition where social capital comprises:

those features of social organisation, such as trust, norms and networks that can improve the efficiency of society by facilitating coordinated actions (Putnam 1993, p.167).
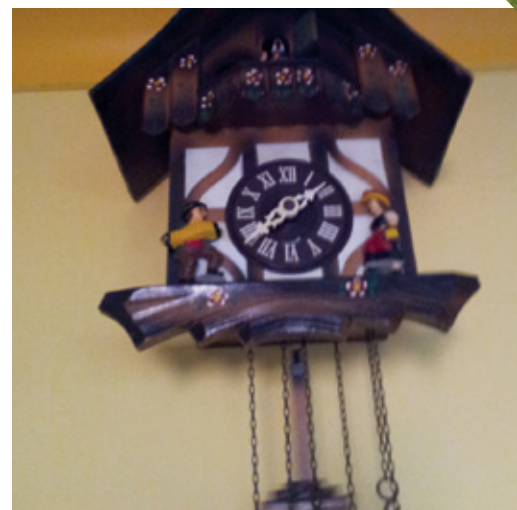
Lewis and colleagues (2013) discuss social capital and its application to social networks and relationships in the palliative care setting. Benefits at different levels include:

- **Micro-level –** bonding networks provide resources and help with daily functions and build trust and a sense of belonging
- **Meso-level –** bridging networks enable access to information and local services and create a sense of community inclusion and cohesion
- **Macro-level –** linking networks provide access to government to obtain resources, increase civic trust and social cohesion, and influence policy.

Research on social capital suggests that rural and regional communities find it easier to mobilise around areas of perceived need (Leonard & Onyx, 2003). People from rural and regional communities have reported unmet needs for support during dying, including inadequate provision of information, fewer options for transport, and greater need for practical care and support (White, 2007; AIHW, 2008). Although this suggests heightened needs may be adequately addressed by rural communities' responses, CCNSW 20 years' experience suggests that issues of privacy hinder mobilisation of informal care networks in rural and regional areas (CCNSW, 2012). This suggests not only the need for further investigation into the particular needs of rural and regional communities, and strategies for managing privacy concerns when they arise, but also the need to recognise the diversity of Australian society more generally.

Social capital, however, is not sufficient to guarantee community development (Mayer & Rankin, 2002). Community development approaches build stronger and more resilient local communities, by empowering individuals

and groups, enabling them to develop the skills they need to affect change in their own communities. If a community is to develop its capacity to both make decisions about the type of support they require, when and where, in addition to providing informal support for those at end of life, it needs knowledge and experience, a sense of empowerment and supportive social structures (Gilchrist, 2000). Genuine community development provides opportunities for experiential, practical knowledge to be developed and stay present within the community, because people have had the chance to become aware of, and further develop, their own abilities, knowledge and skills. This enables communities to utilise available support systems, problem solve, make decisions, and communicate and act more effectively (Kellehear 2005).

Research aims

- To further develop our knowledge and understanding of how informal networks support end-of-life care and to document the impact end-of-life caring has on these networks.

- To identify if and how people's capacity to care for someone at end of life changes as a result of being part of an informal caring network.

- To use these insights to inform public health policy by providing information about the links between informal caring and formal care services at end of life.

- To further the understanding of social networks in terms of social capital and community development theories in the context of end-of-life caring.

Methodology and methods

Participatory visual methods

We needed to be particularly sensitive when asking people to talk about emotional issues that could leave them feeling vulnerable and exposed. Creative methods are increasingly being used in such situations (Horsfall & Titchen, 2009; Horsfall & Welsby, 2007; Davidson, 2004; Yardley, 2008) to provide space for people to speak how they want about deeply felt issues, enabling us to understand what matters and is important to them, and why (McCarthy, 1998, p. 571). Creative methods can also enable people to notice what has become familiar and everyday, to get beneath the surface of things, and articulate the familiar (Diamond & Van Halen-Faber, 2002). This is important, as social relations are often invisible, not talked about, or seen as an unremarkable part of people's everyday lives. We used the methods of photovoice and participatory network mapping in focus groups and interviews to carefully and sensitively document people's experiences in caring at end of life.

Photo voice

Photography is a means by which the unspoken or difficult to speak about can be made concrete (Booth & Booth, 2003). Photovoice elevates the participant to the status of expert in the analysis of their own lives and can be used to enable people to think critically (Freire, 1970), in this case about caring, social networks and relationships. The camera enables participants to tell visual stories, creating opportunities for them to express themselves in their own images, words, and reflections. In turn, these images become points of entry into unexplored areas of life (McIntyre, 2003).

Participatory network mapping
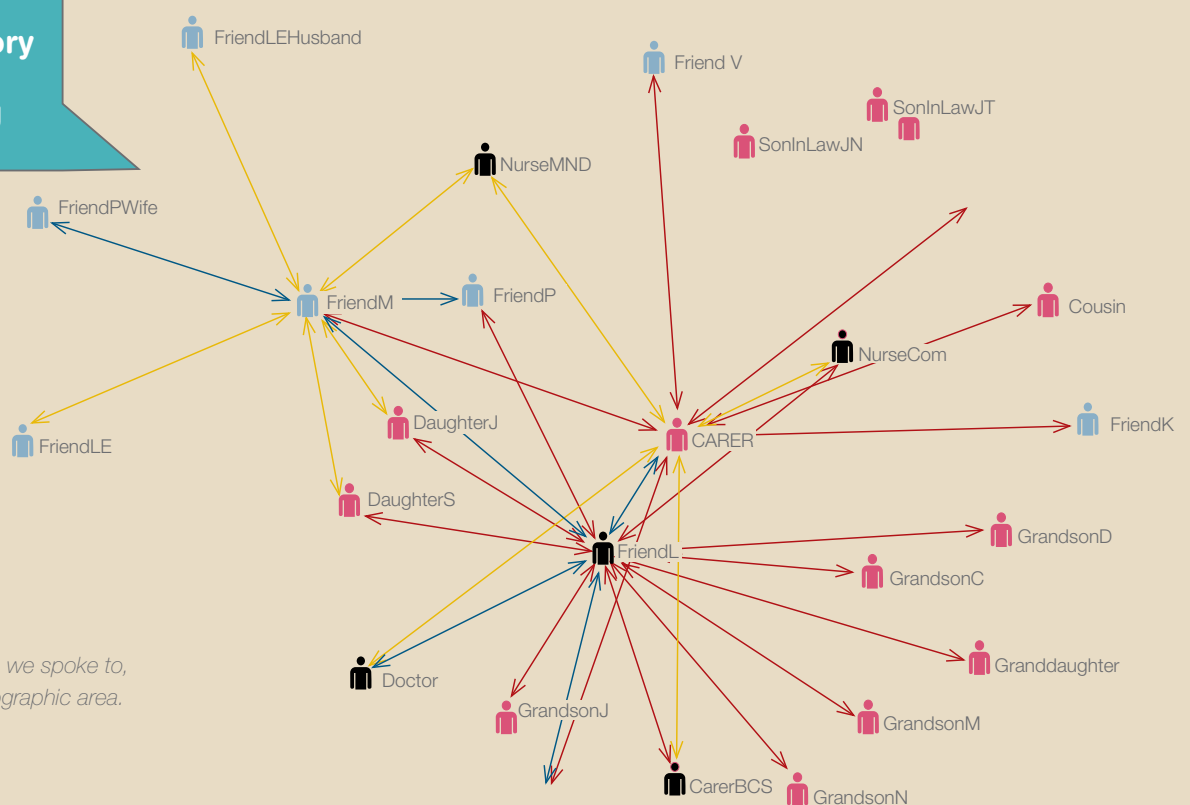
Table 1 showing who we spoke to, in what form and geographic area.

Network mapping is a visual activity that asks participants to map their networks and record changes to relationships pre- and post- caring. Creating the map as a collective exercise allows participants to see the results and provide interpretive feedback about the nature of the networks and any changes they see in size, density and strength of relationship. This allows participants to provide a first level of analysis of the maps during the focus group or interview (Leonard et al., 2013). Furthermore, these maps can later be turned into data suitable for statistical analysis.

Design

Through focus groups and interviews, we collected data from three types of participants – primary carers, caring networks, and outer networks – in eight locations. The research was designed in stages, described below. The locations were chosen because of the differences in levels of formal service provision: the ACT has higher levels than the States, and metropolitan areas, especially inner areas, are better serviced than regional centres and rural areas. The South Coast area, while in NSW, is strongly linked to the provision of services from ACT, so here we hoped to capture regional/rural data applicable to the ACT. The regional centres of Lismore (North Coast NSW) and Orange (Central West NSW) were chosen because they are geographically and socially distinct and have Cancer Council regional offices to support and promote the research.

Stage 2: Face-to-face individual interviews with current or past carers

Apart from promotion of the project by local service organisations, particularly CCNSW, we recruited using advertising in local newspapers. Carers contacted us via an opt-in process and could decide to participate in individual interviews (Stage 2) or to gather their informal caring network as a focus group (Stage 3).

For Stage 2, carers completed the photovoice and network mapping activities (described below) on their own. Participants were provided with a camera and the research questions, and invited to take photographs of significant people, activities or events that occurred as a part of supporting someone at end of life. In the interviews they discussed the visual data and later developed a network map. The interviews explored the nature and role of informal support networks in supporting the dying person and the carer and their attitudes towards end of life caring.

The interviews were conducted by field researchers, CCNSW staff trained by the research assistant (RA), Niki Read. Where a field researcher was not available, the interviews were conducted by the RA or the senior research assistant (SRA), Kerrie Noonan. They lasted approximately one hour, were held in a place of the carer's choosing, audio-recorded and transcribed. Where a carer specifically requested it, we conducted a phone interview.

Stage 3: Focus groups with informal caring networks

Recruitment was the same as stage two. Via the telephone and email, the RA assisted carers to contact their self-identified caring network. For photovoice, the carer and members of the network were invited to take photographs prior to the focus group. Each focus group comprised the carer and their caring network. They responded to and discussed the visual data and later developed a network map. They explored the role of the networks from the network point

of view in addition to identifying changes to individuals and the networks as a result of caring. This stage was a community building research approach where community networks reflected upon their experiences in terms of community and relationship building and their attitudes to death and dying. The focus groups were conducted by the SRA, Kerrie Noonan or by the chief investigator, Debbie Horsfall, with the support of the research assistant. Each focus group lasted approximately three hours and was conducted in a place of the carer's choosing, usually their home. They were audio-recorded and transcribed verbatim.

Stage 4: Telephone interviews with the outer network members

The outer network consists of people who were identified in the focus groups and interviews as the next circle of the network (e.g. school teacher, friends of friends, people who provide social support to the network of carers). Focus group and interview participants were asked to circulate information on the project to the outer network. Participants in the outer network then opted in to the research by contacting us. Each was interviewed by the SRA about their knowledge of the caring situation, the role they played in connecting with people more directly in the caring network and the affects, if any, this network made to their attitudes about death and dying. Network maps were generated at the end of the interview. Each interview lasted about 30 minutes and was audio-recorded and transcribed verbatim.

Participatory network mapping

Two key networking theory concepts were explored: size (the number of people involved) and density (the number of ties within a network).

Ranking caring networks – In focus groups and interviews participants were asked to rank people in their caring network from 0 to 3 to show the strength of their relationship. They were also asked to state the nature of the relationships (e.g. daughter, friend). This form was completed for the network prior to caring and after caring (or the present time). New relationships not initially part of the network but formed through caring were added.

Creating network maps – During focus groups participants translated this information onto two network maps to show the network before and after caring. People wrote their names in a large circle on the butcher's paper and indicated with coloured pens (yellow, blue, red) the strength of their connections with other participants when they became part of the caring network. The process was repeated on the second sheet for connections for the present time. The final part of the process was to 'bring the map to life'

Key procedures for stages 2–4

Photo voice
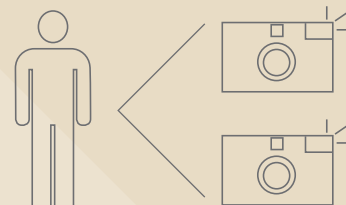
carer **x2 disposable cameras**

Upon deciding to take part in the research each carer was given two disposable cameras with an information sheet about the research and the purpose of the camera (see Appendices 1–6). The carer and members of the network were then invited to use the cameras to capture events, tasks, places and people who were significant in the caring journey. The photos were developed and returned to the community network as part one of the focus groups or interviews. At the beginning of the focus groups/ interviews people were invited to look at all the photos and asked to choose the most significant photos for them, and give these photos a title. The discussion focused on the stories of caring represented by chosen photos guided by a series of questions provided to each carer and caring network (see Appendix 10).

Photos showing people were included only when written consent was obtained from the person/ people depicted in that image.

prompted by questions such as: is there a difference between the two maps? What do those differences mean to you? This immediately gave both the participants and the researchers a full appreciation of role of these networks in the participants' lives and documented the impact on the community.

Analysis

The analysis of the written transcripts was interpretive, qualitative and data-driven. As the participants' voices were central to the analysis, analytical software NVivo10™ was used to classify data into core concepts and categories, with further themes then developed by the research team.

In Stage 2, we looked at carers' lived experiences of having or not having a caring network; what difference a network made to their caring; and how networks were mobilised. We interrogated the data looking for central narratives about caring, about death and dying and about being part of a caring network.

In Stages 3 and 4 we were interested in participants' lived experiences of being part of caring networks. We focused on identifying: What are the central narratives about caring, about death and dying and about being part of a caring network? How did individuals become part of a network? What did they do? How had it affected them, and in what ways? While identifying key themes in the data we also looked for points of departure, difficulty and or/differences in experiences and narratives from the interviews and focus groups. In Stages 2–4 we were interested in any differences in the data between the States and ACT and the urban, regional and rural areas.

Analysis of the network maps initially took place in the interviews and focus groups as participants told us what the maps meant to them and what they noticed. The maps were then analysed using UCInet software to identify the extent and density of the network and any significant within-group changes.

Results and findings

The following two tables provide information about who we spoke to and how. Table 1 details how many people spoke to us as either interview or focus group participants, if they were individual carers, carers in a network, outer network members or service providers and whether they came from an urban or regional part of NSW or ACT. Table 2 provides demographic information about the primary carers, the person they cared for and the place of death.

	Urban	Regional/ rural	Total participants
Focus Groups: Caring networks	5	8	84
Interviews: Carers	19	7	26
Interviews: Outer Network Members	6	11	17
Focus Groups: Service Providers			88
Total	30	26	215

Table 1. Showing who we spoke to, in what form and geographic area.

Key

—— strong ties   👤 formal carers

—— medium ties   👤 family

—— weaker ties   👤 friends
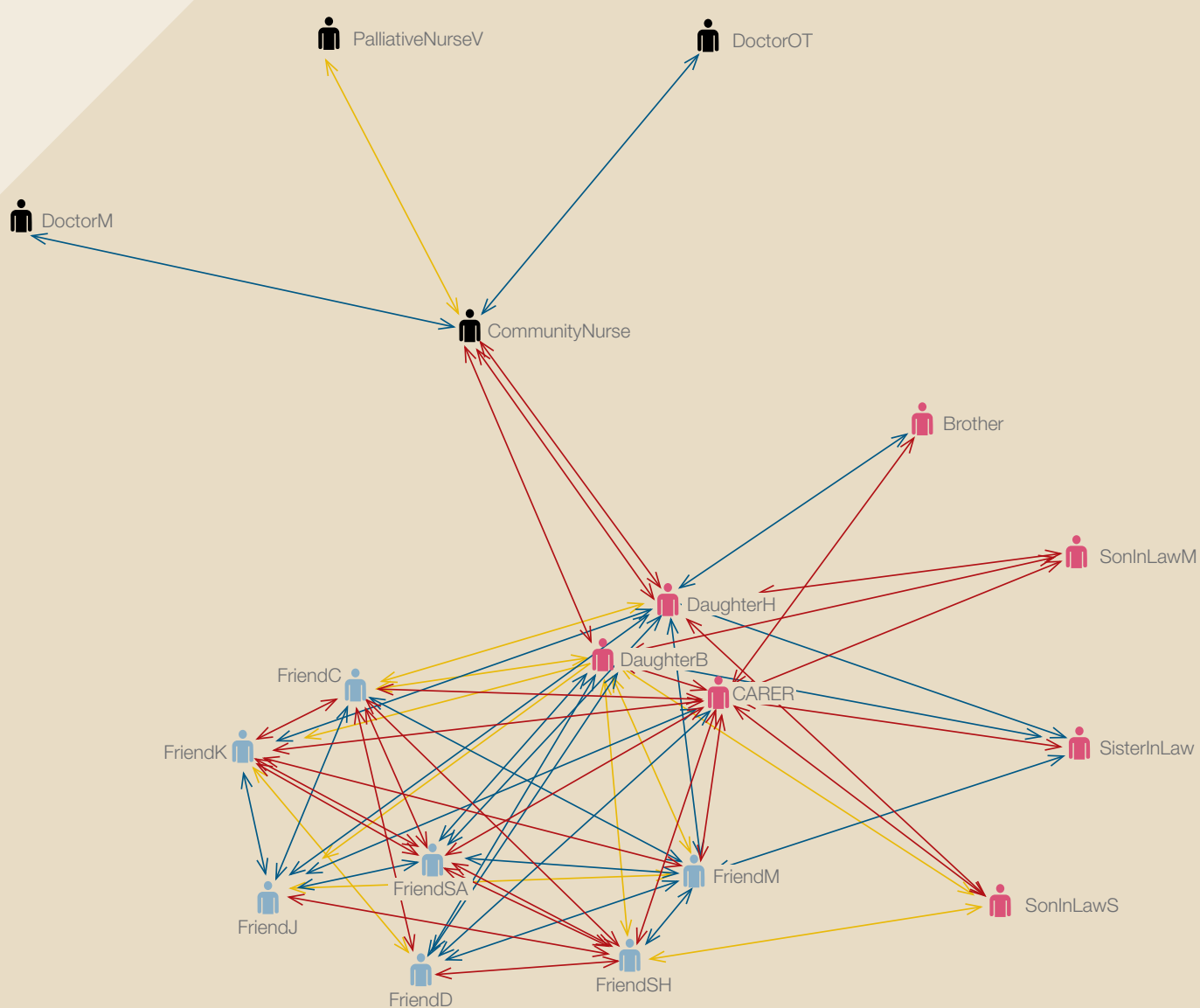
Figure 2. Network Map: Focus Group (FG) 2Regional at time (T) 2 with outer network included

Age of carer	Gender	Relationship to deceased	Period of care	Age of deceased	Illness	Place of death
68	F	Spouse	12 weeks	68	Prostate/stomach cancer	Home
52	M	Spouse	6 weeks	51	Bowel cancer	Home
80	F	Mother	15 months	45	MND	Home
57	F	Mother	4 weeks	26	Complications from multiple handicaps	Home
66	F	Daughter	25 years	84	Cancer	Home
62	M	Spouse	6 months	54	Cancer	Home
64	F	Friend	1 month	69	Cancer	Home
53	F	Spouse	11 months	50	Brain cancer	Home
42	F	Daughter-in-law	10 weeks	63	Lung cancer	Hospital
61	F	Daughter	2 weeks	88	Pancreatic cancer	Home
66	F	Sister	3.5 years	66	MND	Home
64	M	Spouse	3 months	65	Melanoma	Home
69	F	Spouse	23 yrs 4 months palliative	68	Lung cancer	Home
80's	M	Spouse	2 years	80's	Parkinson's and dementia	Home
52	F	Daughter	7 years	89	Heart failure, dementia	Hospital
62	F	Spouse	7 years	62	MND	Home
65	M	Spouse	2 years	66	Lung cancer	Hospital
66	F	Spouse	3 months	76	Prostate cancer	Home
60	F	Sister-in-law	3 weeks	46	Cancer	Home
58	F	Partner	3 months	40	Ovarian cancer	Hospital
65	M	Spouse	3 years	61	Brian tumour	Home
71	F	Spouse	17 years	85	Parkinson's, dementia, respiratory failure	Home
n/a	F	Daughter	5.5 years	85	Alzheimer's, frailty	Home
55	F	Daughter	5.5 months	74	Pancreatic cancer	Home
52	F	Spouse	3 months	55	Melanoma	Home
65	F	Spouse	3 months	60	Pancreatic cancer	Home
60	F	Daughter	3 months	83	Mesothelioma	Home
64	F	Spouse	6 months	67	MND	Home
65	F	Spouse	10 months	62	Brain tumour	Home
53	F	Spouse	5 months	70	Mesothelioma	Home
72	F	Daughter	7 months	92	Organ failure	Family member's home
52	F	Daughter	5 weeks	73	Bowel cancer	Home
70	F	Mother	1 month	45	Cancer	Family member's home
48	F	Daughter	2 months	82	Heart failure, dementia	Hospital
67	M	Spouse	3 months	70	Cancer	Home
72	M	Spouse	2 years	69	Emphysema	Home
48	M	Spouse	3 years	47	Breast cancer	Hospital
49	F	Daughter	6.5 years	83	Renal failure	Home
68	F	Daughter	Father 20 yrs; mother 5 yrs	Father 93 Mother 91	Heart failure	Home

Table 2. Showing age and gender of primary carers; relationship to deceased person, length of time caring, cause and place of death

In total we spoke to people representing 39 caring networks across NSW and ACT in urban, regional and rural areas. Of these networks, 33 cared for someone who died at home and 6 cared for someone who was dying at home but who ultimately died in hospital. In some of these instances people were keen to tell us why a hospital death had occurred: "Mum had several trips to hospital by the ambulance in the weeks before her death. The day before she died she was taken by ambulance again and died the next day. The hospital never rang us to tell us she was going and so she died on her own. She wanted to die at home and we tried our best to enable this to happen but we needed more support from palliative care" (carer interview urban).

Gender breakdown – Thirty of the main carers were women: mostly spouses/partners (n=12) with the next largest group being daughters (n=11) and mothers (n=3). Sisters, sisters-in-law and friends made up the total. Men in our research were only primary carers for their wives. In the networks, men did play key roles as friends and sons but did not identify as the main carers. The youngest carer was 42 at the time of the research and the oldest in their 80s (they declined to tell us their exact age!) with the majority being in their 60s. In terms of length of time caring, the range is such that it is difficult to say anything very useful.

Diagnosis breakdown – The majority of the people who were cared for died of cancer of some sort (n=24) with dementia/Alzheimer's disease being the next largest group (n=5) and Motor Neurone Disease being the third largest (n=4). This is not surprising as our research partner was the Cancer Council of NSW who was active in promoting the study through its offices throughout NSW. We also had an established relationship with MND NSW from our previous study. It too was active in recruitment. What did surprise us was the representation of people who had dementia and Alzheimer's disease and who were cared for to die at home.

Mum had several trips to hospital by the ambulance in the weeks before her death. The day before she died she was taken by ambulance again and died the next day. The hospital never rang us to tell us she was going and so she died on her own. She wanted to die at home and we tried our best to enable this to happen but we needed more support from palliative care.

Carer interview, urban

Discussion of themes

At the conclusion of six years of research, 308 people have participated in this unique end-of-life research, providing in-depth personal and collective narratives about the function and effects of informal caring networks. We found that, despite the prominence of a medical model, carers have the ability to 'do it their way' and step outside of institutionalised dying. With no prior knowledge or special skills, they showed their ability to care for a person at the end of their life at home. Carers demonstrated they could seek out information and learn the complex physical and emotional end-of-life caring skills.
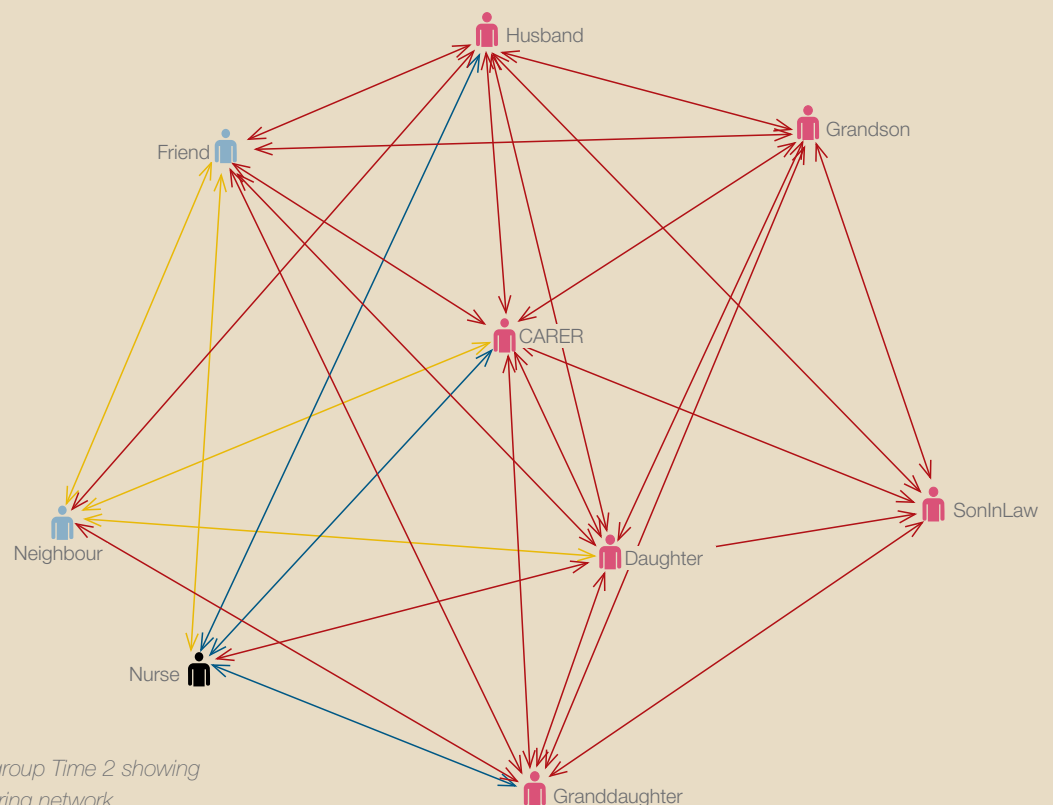
Network map: Regional focus group Time 2 showing the nurse integrated into the caring network

Theme one: Networks

Care networks: What people do

We found that carers themselves coordinate services, but not always the networks or community responses. Informal networks come together in a variety of ways; some are galvanized into action by existing community groups (faith groups, clubs, organisations), others just 'notice' there is a problem, or are told there is a need and then offer what they think will be useful.

Knowledge about what to do and how to do it seems to be based on being existing members of a community and having helped people through life's ups and downs before. People show up and do what is needed, even when carers or the dying person have initially resisted. These acts of kindness are greatly appreciated and reciprocity is evident. There is a strong sense of those in need 'deserving help' from their community, particularly when the dying person was 'well loved' 'well known', had worked hard and contributed to their workplace and/or community. People felt it was just 'right and proper' that they show up and help out.

Community members and informal networks

People offer support to the carer and the dying person according to their skill base and in the following ways:

- **Provide domestic support –** cooking, cleaning, gardening, mowing lawns
- **Practical assistance –** transport to medical appointments, picking children up from school, minding the dog, doing the shopping, helping with renovations and modifications, constructing ramps, putting up handrails, sourcing information
- **Offer emotional and spiritual support –** visits and phone-calls, sitting with and providing companionship to the dying person, lending a non-critical ear to the carer, or a shoulder to cry on
- **Providing expert care –** helping with medications and personal care.

Principal carers

Principal carers often take on tasks that many of them would never have dreamt of undertaking and in everyday circumstances they would find overwhelming and even terrifying. This includes tasks such as administering injections, narcotics, dressing of wounds, and the most intimate of personal care.

Norms of privacy, 'keeping it in the family' and a conventional view of personal agency are thrown to the four winds in favour of practical solutions, conserving energy and embracing collectivity.

Relationships

The intimacy of caring brings a new level of intensity to relationships that changes the way people feel about themselves, the dying person, and their community. Networks come together for a specific time period and purpose and operate like an elite frontline team, often describing themselves in those terms. When the person dies, relationships change again – some continue with deeper bonds, others dissolve once the focal point of their attention and commitment is gone.

It was a shock to some carers when they reviewed the relationships that had been so significant to them throughout the time of caring – often the most intense of their lives up to that time – to realise that some of these relationships had 'shrunk' and moved away. A sense of loss accompanied the understanding that those networks were transient and acceptance and release was, at times, difficult.

Embarking on a caring partnership brings life into sharp focus – the quality of the time spent together and being 'up to the task' becomes the primary objective in a single-minded locus of activity. The network and the care environment become the still point in a turning world.

We had the oxygen machine with electricity and for some unknown reason – the first time it was a car accident – the power went out because the telegraph pole had been taken out. So the people next door came and asked if there was anything they could do and they'd already rung the electricity provider to tell them that Mum was on oxygen and we needed power.

Carer 14, urban 2

Carers often fiercely protected the bonds of love, determined to maintain loving touch, and fill their homes with as much fun and laughter as circumstances allow. They often used ingenious and creative ways to keep a sense of lightness in their lives and the life of the dying person – who was often the instigator of jokes, parody and black humour. Games were played, music made and many intense, thought provoking discussions stumbled into in the stillness of the early morning.

Struggles

Carers struggle in their role on a number of fronts.

The barriers and challenges confronting them can be geographical and economic; issues around service provision and rules and regulations; access to information and timely advice; the need (and desire) to maintain employment; problems within families and neighbours, capacity within communities to provide care and support; living with the emotional impact of their own and other's expectations.

When caring networks have successfully implemented strategies to overcome these obstacles, the long-term effects of anxiety and stress have been lessened.

Significantly, the greatest struggles carers reported experiencing were with hospitals, GPs and other formal medical services. The impacts of these institutional struggles have a long lasting impact – at times bringing carers close to breaking point.

▼ Economic barriers

I feel really strongly that the government needs to take it on a case- by-case basis. They didn't release her superannuation until after she died. She applied twice and they knocked her back - she couldn't even get a percentage. I mean how dead do you have to be?

Carer 7, urban 2

▼ Lack of capacity to care

My Dad was still alive when this was said, "We don't want to come and see your Dad because we don't want to remember him that way". I thought it was the biggest load of crap I've ever heard in my entire life – because he wasn't dead! He still had his brain and he could still think and hear what they were saying!

Carer 11, urban 3

Geographical spread of networks

The geographical spread of services and networks impacted carers in positive and negative ways – providing more choice in some instances and less access in others.

Family and friendship support networks located interstate or overseas used social media to provide support from a distance. This allowed networks to remain close, with sometimes significant discussions occurring via email or Facebook (e.g. planning farewell visits, funeral services, carer reunions).

Lack of community capacity to care

Reasons for a community's lack of capacity to care included:
- inexperience (not knowing how to provide practical help)
- lack of emotional maturity or resilience (inability to face the reality of impending death, or trust in their own judgement)
- social isolation or lack of social capital (of the dying person, the carers, or potential network members)
- lack of community cohesion.

Carers found caring more difficult and exhausting when communities failed to provide support. When this occurred, carers felt burdened by the failure of communities to care – disappointment and resentment sometimes affecting relationships long term. Disappointment was most potently felt where support (such as from faith groups, family members or long standing friendships) might have been reasonably expected.

> We were trying to work between two area health services and that just made life really interesting.
>
> *Carer 12, urban 2*

▼ Lack of acknowledgment

"Oh we don't want to upset you, we don't want to remind you". I never forget. I don't. So you can't remind me. In fact what's worse is when you don't mention it and you deny what's still a huge part of my reality.
Carer 12, urban 2

▼ Support when it's needed

It goes through a hospital system and not our health system, it's really slow – and she's dying really quickly.
Carer 19, urban 2

> I think I was kind of scared … I think that was it. I wouldn't – this is about me – that I wouldn't be up to the task, and I thought 'well everybody thinks I am, so perhaps I am'. But I did find it a bit kind of scary and I think that the other things I was also a bit scared about was that she might die when I was there and I might be the only person with her. Would I do that right – or would I go in and find that she had died in her sleep? Those were the kinds of things that I suppose made it hard for me.
>
> *Focus group 7, regional 4*

Economic barriers, employment and other commitments

The financial impost of caring is considerable for many, and an insuperable barrier to some – with families often losing the income of both the principle carer and the dying person at a time when many of their household expenditures increased. Many carers relied heavily on the willingness of their employer to provide flexible working hours and extended leave periods so that they could be home when needed. The lack of financial support for families in need was the source of anger and frustration. Carers in financial need felt a sense of great injustice if their own and/or the dying person's contribution to the community, often over many years as earners and taxpayers, were not recognised through the provision of financial assistance.

They resented having to jump through what they saw as bureaucratic hoops to obtain assistance, particularly when financial need was immediate and severe.

Information

Information is often difficult to source, inaccurate or found too late to be useful. One carer spoke of the difficulty of getting information about sourcing and arranging palliative care, with palliative carers finally arriving three hours before her mother died. This carer felt that the system had failed them severely. Timely, unambiguous and accurate information was highly valued and appreciated by carers and the network. Many commented that accessing all relevant information about services, supports and care strategies from one place at one time would be extremely useful and save many hours of their precious time.

◢ Economic barriers

People need financial help – we're saving the government a lot of money.

Focus group 2, regional 2

◢ Lack of information

I think there's a gap between needing the help and getting it. Who gives you that help? Who gives you that guidance? Information should be central and in plain English; 'This is what you need to nurse someone at home'; 'These are the steps – this is what we can provide'; 'This is what the government can do'; 'This is what the council can do'. You shouldn't have go all over the globe trying to find services.

Focus group 11, area 3

Personal anxiety

Carers often feel anxious and fearful, and these emotions are accepted as an inevitable and unavoidable part of the caring process. They are fearful of the moment of death itself and of their own limitations: 'Can I do this right?', 'Am I up to the task?', 'Will I make a mistake?', 'Will I be found wanting?'.

They take on the role despite these, often persistent, fears and describe the constant self-chatter, and self-reflection and reinforcement that get them through the frantic and scary days. Anxiety can escalate towards the end for both the dying person and the carer, and the support of formal and informal networks becomes crucial.

Lack of acknowledgment of end of life

Issues emerge for carers when others deny or fail to acknowledge end of life, e.g.
- a GP, in the interests of a patient's sovereignty, fails to diagnose dementia, services are not forthcoming
- if hospitals see the patient in terms of crisis intervention and ignore the bigger picture, eligibility for supports and services can be effected
- if friends and family won't visit for fear of what they might encounter, or a desire not to face the reality of death, the carer and the dying person are left without support they might have otherwise expected.

Carers are greatly frustrated and angered when this kind of denial of reality interferes with their capacity to care well.

Personal anxiety

There was some anguish around the inability to do anything that really helped him. I found that a very difficult part of caring for him. I could make a boiled egg or the port wine jelly or whatever it was he needed but I couldn't make him feel more physically comfortable. I couldn't take away the effect of the drugs or ease the sense of physical frailty or the bones that hurt. I found that extremely difficult to cope with emotionally. I suppose in a way there was a big lesson in that for me – that sometimes no matter how good a person you are or how hard you try or how good your intentions are, you just cannot achieve what you want to sometimes.

Outer network 9, urban 4

Theme two: Service providers and networks

The interactions between informal caring networks and service providers formed a key theme in this study. We defined 'formal' service providers as health care professionals, including:

- general practitioners (GPs)
- members of palliative care teams (based in hospitals and community settings)
- community nurses
- pharmacists
- massage therapists
- home care services
- others who have specified roles to provide services for people at end of life.

In this project, participants identified the benefits and difficulties they encountered when formal service providers were involved in the care of the dying person. While the data speak strongly of the role of these providers as individuals or even as groups of individuals (rather than as organisations), the challenges of navigating the health care system were substantial.

Relationships with formal service providers revealed in network diagrams

In most cases, formal service providers were identified as part of the caring network. In almost all cases, service providers were on the periphery of the maps, indicating that ties were weak compared to family and friends. While there were no significant differences between the density of networks among family members and friends, there were significant differences in the density of ties between family members and service providers (focus groups t=3.00 p=.03; carers t=3.146 p=.009. NB this only includes those networks that named formal service providers as part of the network).

No formal service providers – Four focus groups and one carer identified no formal service providers in either the transcripts or the network diagrams.

Formal service providers not included – While six carers talked about service providers in their interviews, they didn't put them on their network maps, suggesting that they didn't see service providers as part of the caring network. Focus group 8 is a good example of the separate worlds of the informal network and the formal service providers. When the community nurse was interviewed as an outer network member she identified three formal service providers (a palliative care nurse and two doctors) as additional contacts. These contacts were known to the informal caring network, but were not identified as part of it.

Relationships strengthened with formal service providers – There were eight examples where the strength or number of ties with service providers increased from Time 1 to Time 2. When ties strengthened it was generally with community and palliative care nurses. In one case, a friend became a formal service provider. This seemed to have the effect of drawing other formal service providers more closely into the network.

Relationships did not change – There are three examples where the number and strength of ties to service providers stayed the same from Time 1 to Time 2.

Relationships decreased – There were 12 examples of carer or focus group interviews where the strength or number of ties with service providers decreased from Time 1 to Time 2. Interviewees often commented that after the death there was little or no further contact with formal service providers. This was a defining feature of formal service provision reflecting the social impact of funding models of palliative care that do not include bereavement support.

_____

They (palliative care team) gave us a hospital bed, a commode, a chair – one of these recliner chairs – a wheelchair. They organised for somebody to come in and put handrails in the shower and put a new thing into the shower so that I could shower him in a chair. Everything! They provided all of those things and they organised it.

Carer 13, regional 4

_____

37

Benefits from formal service providers

Carers and network members received support in various ways including:

- clinical care (e.g. pain management)
- training in clinical tasks (e.g. administering injections)
- organising equipment and other home modifications for care
- providing advice.

In particular, carers valued accessible, truthful advice and personalised care for the dying person. For instance, some procedures were adjusted so they could be completed at home and an onerous trip to the GP or hospital avoided.

Through formal service providers, carers accessed services that they did not previously know existed. There were numerous examples of service providers coordinating a whole range of services mainly for the dying person but sometimes for the carer as well. Carers were relieved when formal service providers endorsed their work so they knew that they were adequately managing the practical side of caring.

Carers found access to around the clock telephone advice reassuring. Even if that service was rarely used it was a great comfort to carers to know there was somebody to ring, in case of an unexpected problem. Some service providers also attended to the carers' needs by providing emotional support. It was appreciated when they were honest about the dying person's condition and sometimes it was easier for the service providers to talk to the dying person.

> I would ring palliative care 'cos there was a nurse on 24/7 and they would say. 'That's normal'.
>
> *Carer 11, urban 3*

Benefits

By understanding the dreadful trouble I was having with the doctor and the medication – understanding how important the medication was. It's essential – it was the basis of her pain relief and he understood what I was up against because he could see that I couldn't get her to and from the surgery, so within the realms of his registration obligations, he just helped me organise care that was going to be sufficient and then by always keeping his word. That's so essential – if somebody says, 'I will be there when you call me', and they do come.

Focus group 5, regional 2

Navigating the system

Carers and network members described several challenges in their interactions with formal service providers.

- Carers found they needed to understand the system and preferably have some inside contacts to get the help they required.

- Being known personally by formal service providers greatly increased the quality and flexibility of services.

- Carers who had worked in caring services, had a relative in the health field or who had built up a network through years of caring, felt they had an advantage in accessing the services they needed – a process of learning how to navigate the system, developing critical health literacy skills.

Disruptions to relationships

Sometimes service providers were actively obstructive, trying to dissuade the carer from providing care at home. In these instances, carers had to actively resist these attempts at control. The relationships between the carers and the formal service providers could be weakened or disrupted by poor services or inappropriate services or insensitivity of the service providers. The psychological impact of a terminal diagnosis could be worsened by the resistance of service providers towards supporting the decision for care at home. This was particularly true of hospital services.

That's the wonderful thing about getting a pharmacist that gets to know you and knew what was going on in our lives. That's a huge thing.

Carer 18, urban 4

◥ Navigating the system

We had the oncologist, palliative care specialist and the doctor in charge of the ward and then we had the psychiatrist in the end as well, and the social worker. They were all adamant that she shouldn't go home and I was fairly determined that I wouldn't send her to a nursing home.

Carer 8, urban 3

◥ Navigating the system

When you get the death sentence no matter what form, that's the biggest kick in the heart you'll ever, ever, get and then the ultimate kick is 'We're going to push you into a hospital and you're not going to get to choose your bed, your bed mates or anything like that. You'll take the care that you're given'.

Focus group 2, regional 2

> Professionals are supposed to not get involved but we cared for the man and the nursing service is a business. So there was this real divided between us and 'them' and it just got worse and worse.
>
> *Outer network 16*

> It needs to be done right for me to want to do it at home, and I've actually said to patients in the past, "No we're not doing this, we're off to hospital".
>
> *Nurse, Focus group 5*
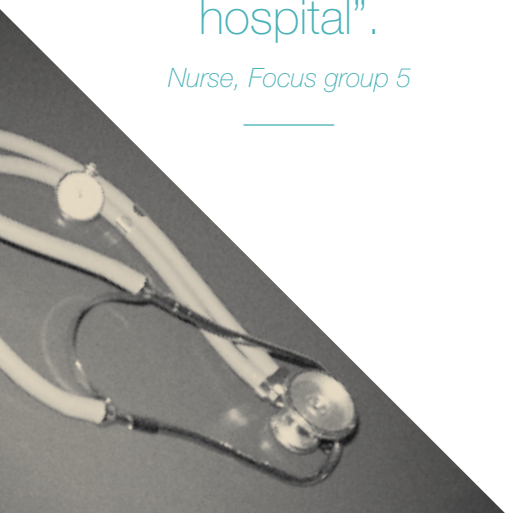
There could be conflict between the personal approach of the informal network and the professional approach of the formal service providers. Carers and network members reported fractured relationships with formal service providers, who expressed a view that non-professionals were not capable of giving appropriate care to the dying person. This discrediting of the carer's role was the source of anguish amongst some study participants.

Even good relationships with formal service providers usually ended abruptly when the person died; this could leave carers feeling deserted or struggling with daily tasks. While many carers understood this termination of the formal caring relationship, a number expressed a desire that the relationship not 'disappear'. This was especially true where the connections were strong and the place of the formal service providers was well regarded by the carer and their informal network. One carer stated, "Obviously the formal ones have withdrawn, but a couple still maintain contact" (Carer 9, regional 4).

Providers trained not to 'care' too much

An issue which influenced whether formal carers could become bonded into the caring network was the distinction between 'care as service provision', often associated with the medical model and expectations of professionalism, and 'care as relationship building', with the latter being necessary for the creation of social networks (Horsfall & Higgs, 2014).

The relationship between end-of-life care service providers and communities largely remains a paternalistic one, with the expert-recipient dyad predominant in Australia and elsewhere.

Zapart et al., (2007) note that it is a challenge for health professionals to identify the support needs of carers without replacing the carers' role. Even when formal service providers have a positive regard for informal caring networks, they typically keep their distance and play a minimal role in mobilising, supporting and maintaining these networks (Horsfall et al., 2012).

Professionalism anti-care

Several participants felt the formal service providers actively obstructed their efforts to provide care in the home. The 'professionalism' of formal service providers was seen in contrast to the informal provision of support by carers and network members. On some occasions, this divide meant the withdrawal of formal support if patients did not comply with the directive to be admitted to hospital.

When it works, it really works

It became clear in this study that the relationships between networks was a key factor in accessing the full range of services available, providing carers and the dying with the support they needed to die comfortably at home.

When formal services were well integrated within the informal caring network, good outcomes were achieved for the dying person, their carer and the network members. Significantly, the importance of integrating formal services within the caring network – not the other way around – was evident, countering the paternalism inherent in many models of health care.

When the importance of the caring network was recognised and facilitated, relationships between formal service providers and informal networks were strengthened throughout the caring process. For example, people felt very satisfied when GPs were attentive and respectful to their needs and connected them to useful support services.

Interestingly, if the dying person was adept at building social capital – assisting the carer to care for them rather than being a visitor in the process – if there was reciprocal interaction, the carer was better looked after by both the formal service providers and informal networks, and bonds were stronger.

Palliative care workers in the home were reported to be skilled at enabling relationships and played an important role in integrating formal service providers into home-based informal care networks.

The strength of informal care networks is one of the main factors that carers identified as having a significant influence on their capacity to last the distance – and survive the caring role relatively intact. While carers take the primary responsibility for timetabling and coordinating all aspects of care, some found the coordination time consuming and stressful. Where formal service providers embraced the care ethos of a household and assisted in and supported the carer in their coordinating role, relationships benefited and provision of care was more streamlined.

His GP loved Thomas very deeply. It was a very, special relationship. At the end of the day - every day – he would call in on the way home to see Thomas and ask, 'Is there anything you two need, are you OK?' He would pat my shoulder, let me cry, say, 'F…' quite a few times. He cried as well - a lovely, lovely man.

Carer 5, regional 3

Theme three: Death literacy

Death literacy, first described in Horsfall, Leonard and Noonan (2013), is a useful conceptual framework for describing and understanding the outcomes of a network approach to end-of-life care in the home.

The concept emerged from our previous research when we analysed the transformative effects of participating in a network of friends and family caring for someone dying at home (Horsfall, Noonan and Leonard, 2012).

Defining death literacy

We define death literacy as a set of knowledge and skills that make it possible to gain access to, understand and act upon end of life and death care options.

People and communities with high levels of death literacy have context specific knowledge about death and dying and the ability to put that knowledge into practice. This putting into practice is a form of social action.

In this research, we also found that carers and their networks were actively engaged in a critical learning process through which they developed the knowledge and skills required to care for a person to die at home. The result of this learning is what we call a form of 'practice wisdom'.

Death literacy then is an outcome of people's experiences of, and learning about, death and dying. Once this happens, death literacy becomes a resource that people and communities can use, thus strengthening their capacity for future caring.

What is central is that it is the *active participation in caring* (in its many forms) that enables the development of death literacy. This learning is the outcome of genuine community participation in the care for a dying person.

You can't do things for somebody and then expect them to know … They've got to be able to do it. If they're hands on it's a different kettle of fish.

Outer network 8, regional 4

Transformational learning

Caring at home, where carers are able to be hands-on with the dying and dead person, provides an embodied learning experience that invites reflection and meaning making. This reflection and meaning making was extended by our research in focus groups and interviews. We heard many stories about how the experience of caring transformed the behaviours, attitudes and beliefs of carers.

For example, dying was demystified and seen as a more normal part of life, and people learned that they could trust their community to 'step up' and provide what was necessary.

This learning was enhanced by being able to draw upon the skills of other network members and, when needed, health professionals. The key here was that people could access information and support on their own terms and they trusted that the network would provide what was needed during the caring journey.

What caring networks learned

When asked what they had learnt from the process, most people mentioned the following:

- learning how to live more deeply and fully
- appreciating the moments
- not worrying about if the washing was done or not
- developing a tolerance for themselves and others to 'not sweat the small stuff'
- to listen deeply
- they were capable of showing up and doing the work that needed to be done even when, at times, it was overwhelming.

In essence, they said they had changed as people.

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I think too that no matter what you've been explained, no matter what, it's still completely different to what you're experiencing.

Focus group 8, regional 1

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As researchers this change is both gratifying and frustrating, as it is difficult to quantify. But perhaps what they were telling us was how compassionate communities develop and grow?

This learning, and the associated benefits, were seen to be collective and cumulative; that is, the community grew and developed in its capacity to be compassionate as people experienced informal caring. Carers actively sought out knowledge from their support networks, including technical knowledge about medication, nutrition, self-care and the dying process.

While carers had varied ways of learning, interestingly health professionals were not always used to support carers' knowledge. The exception to this was if the knowledge involved a medical or nursing intervention that benefited the patient in some way, such as pain or bowel management.

Learning skills
Carers developed skills in the following areas:
- **practical support –** personal care, medical care, active engagement in dealing with the body after death
- **emotional support –** communicating about end of life, talking about death, discussing dying and illness, and planning for death and dying
- **negotiating support –** asking for and negotiating both professional support and the informal support of their family and friends
- **organising place of care and place of death –** for some carers this meant resisting the 'system' in order to continue to care at home and for many there was a need to display a high level of assertiveness and confidence, especially toward health professionals; this was often made easier with the support of the network.

I talked to everybody … I tell everyone because I just had no idea that that's what went on at home … I'd never seen it before. I mean everyone I've lost I've lost them in hospital … So I'd never seen anything like this before and I tell everyone. Just amazes me!

Focus group 2, regional 2

Social action

Network caring for a dying individual can be a catalyst, or an opportunity, for people to develop literacy about death and dying. In particular:

- individuals share knowledge and skills with other social networks
- 'we know what to do' – caring networks were more easily mobilized in the future when care is required. We found evidence that people who had cared before recognised they were better equipped for end of life care and they felt they were able to re-engage with social networks if, and when, required
- individuals are primed for taking action about their own end of life plan.

Our research suggests that death literacy develops across the network of carers, including those in the outer network.

The outer network of informal carers plays an important role in transmitting knowledge about death and dying into the community. Until now, this group of informal carers and supporters have been rarely mentioned in the literature. However, we also found evidence that people in the outer network observe and learn from the inner network. A potent example was provided by a pharmacy manager who was identified, by a carer, as a member of the outer care network.

All of this had a cumulative effect, where caring networks were transformed through relationships, knowledge sharing and the feeling that people were supporting each other in something extraordinary. The informal caring networks and relationships underwent transformation as a person was supported to die at home. This transformation occurred as social relations and networks were mobilised to support and help with caregiving and as people developed their literacy about death and dying.

Mobilising, using and developing caring, or compassionate, informal networks through active engagement in tasks promotes a model of change which moves away from the more usual health promotion approach which is to 'educate the community' so that they can participate. Rather, this model of change supports networks of people to participate in the day-to-day tasks of caring for people. This transmission of knowledge requires social action.

Networks

We have previously referred to inner and outer members of the caring network (Horsfall, Noonan & Leonard, 2012) and defined them as follows:

inner network – family and friends involved in the intimate care of the dying person and their carer

outer network – larger and more diverse group of supporters, which often supports the inner network.

Dying person as teacher

Caring at home for a dying family member develops knowledge and skills about the death system. Death literacy is also the outcome of didactic education. However, experiential learning contributes to a deeper understanding of how a society 'does death' and to the changing attitudes and actions about death.

Caring at home, where caregivers are able to be hands on with the dying and dead person, provides an embodied learning experience and invites reflection and meaning making. We heard many stories about how the behaviours, attitudes and beliefs of carers and their networks were transformed by the experience of caring, including:

- seeing dying as a part of life
- normalising the experience end-of-life caring at home and home death
- a deeper appreciation for the role of friends, neighbours and family when caring at home
- a deeper understanding of how many people can be involved in caring for a loved one at home.

This learning was enhanced by being able to draw upon the skills of other network members and, when needed, health professionals. The key here was that people could access information on their own terms and they trusted that the network would provide support and information needed during the caring journey.

When Louise laughed she would just make everybody laugh. She just used to go into this hysterical laughter and she'd look at her mother and she started laughing and Hannah started laughing back with her and it was just like this beautiful symphony of them both just laughing and laughing and laughing!

Focus group 4, regional 3

Triumphal discourse

The way that carers and care network members spoke about their experiences following the death was often in triumphant terms – we made it, we got through, we did the job well and it changed us forever.

The many reasons people give for choosing to care for friends and relatives at home are a significant factor in the way stories about the experience of death and dying are framed – keeping faith with their loved one's wishes, honouring friendships, walking beside someone to the end, sharing one of the most significant of life's journeys.

The triumphal discourse is clearly distinguishable from a discourse of survival and trauma. While the sense 'that we survived!' is present and the traumatic moments are described in vivid detail, the emotional impact of those experiences are transformed through the telling.

Carers want to acknowledge, to themselves and others, that they transcended their fears, overcame their weaknesses and limitations, learnt what they needed to learn at a run, loved to the best of their ability and held firm on the biggest roller coaster ride of their lives.

I've grown a lot or learned a lot – all the stuff I know now that I had no idea about. Makes a really big difference.

Focus group 8, regional 1

The bling's the thing… a love affair…and a house

We fell in love with this house, as soon as we walked in the door. It was red and white with a red roof – looked horrible, but we fell in love with it anyway. I'd never owned a house before or was ever even interested – always had itchy feet.

We knew Jay had cancer when we moved up here. She was really keen for me to be settled. There was no garden, so we had the landscaping designed so that she could see through the bedroom window while it was being planted, all Australian natives – except for the roses. Jay loved roses, all through the garden, all through the house. She could see the garden when she was dying. When I downloaded her phone after she'd gone there was a picture of the view from the window that she liked and one from the window of the hospice that she died in.

Jay's family home had been dark and she loved light coming into a room. That was one of the things that we noticed when we came to look at the place – there was light streaming through the kitchen. We had to find a way to renovate the terrible bathroom. I had this motorbike (I loved that bike!) so I sold it and we made the bathroom wheelchair accessible. I was so grateful for that renovation.

There is so much of her around this house. Her spell book, I bought her that, signed by the author. She was very witchy and her mother too. She loved all that stuff – smudge pots and spells and crystals. She was a bit of a disco babe when I first met her, famous for her glow sticks. It's the 'bling thing' – sparklers, sequins – anything shiny. We had big parties for Yule Fest – always with glow sticks at night. I still had so many sparklers after she died that I had enough for the memorial service. I handed them out to everybody. Then there are the elephants – pencil cases, bags – elephants everywhere! She loved those elephants; and special things like our wedding rings. Mine's rose gold and Jay's is yellow gold with matching forget-me-nots. Her diamond earrings she wanted put into a ring. I can't decide if I want to put them in her wedding ring – I'm not sure.

There are the not so pretty things too, that you end up with, like the vomit bags and the thermometer – for taking of temperatures for chemo. That was just the sickness type of stuff. She had a lot of skin problems – she was allergic to morphine, which would bring her out in a rash.

Our last fight was over a cupboard. She wanted to fill it up, crowd stuff in – I wanted clear space. She was a very forceful personality. I don't remember ever saying, 'No', except when she wanted to buy a million dollar house, then I did put my foot down.

We considered ourselves married, though not everyone would. We had a commitment ceremony near the apple orchards – 'cause we had courted up there – it was such a lovely day. I call myself 'Mrs' and that's just the way it is, anyone who thinks that's not OK can just suck it up!

Those are my two big bugbears, I think. Even though Jay had worked for eight and a half years with diagnosed cancer and paid big taxes, when push came to shove and Jay left work, we were on the bones of our arse. We were really, really struggling – no government support at all. That's a big one – it made me so mad. The other is the fact that people don't necessarily understand grief very well. Once the person's died they feel like the job is done, 'we got her through this'. They don't rally around the person who's left. People just disappeared.

The strong things were family, my neighbour down the back, one of the places that I work, friends who paid for a holiday for us, for a non-chemo week by the water, so generous and so wonderful – and my Mum. She was fantastic. I wouldn't have liked to have done that end-of-life caring on my own.

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She was a bit of a disco babe when I first met her, famous for her glow sticks. It's the 'bling thing' – sparklers, sequins – anything shiny.

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Theme four: Social capital and community

People are already active members and part of their community – whether through work, encountering one another in the street, out shopping, or as members of groups and organisations.

There is a strong sense emerging from the data that carers and members of caring networks know the importance of relationship – of giving and receiving and providing support to others.

Simply by their proximity to one another, or through their chosen affiliations, people have been through life's ups and downs together. Social capital has been built through these every-day experiences and activities that is accessed in varying degrees by carers, depending on their level of connection with their neighbourhoods and networks.

Only 19 of the 36 networks included community members who were not neighbours or service providers, suggesting that there is scope for such relationships to be developed more widely. As might be expected, the density of the relationships between family or friends and community was significantly less than the relationships among family and friends. Although there were fewer relationships with community than with service providers, they tended to be stronger so the community members were less marginal on the network diagrams.

Forms of support

- **Employers and workplaces –** stepped up to support carers and terminally ill workers through flexible work hours, working from home, and through caring colleagues and bosses who often provided practical help around the home as well as support at work.
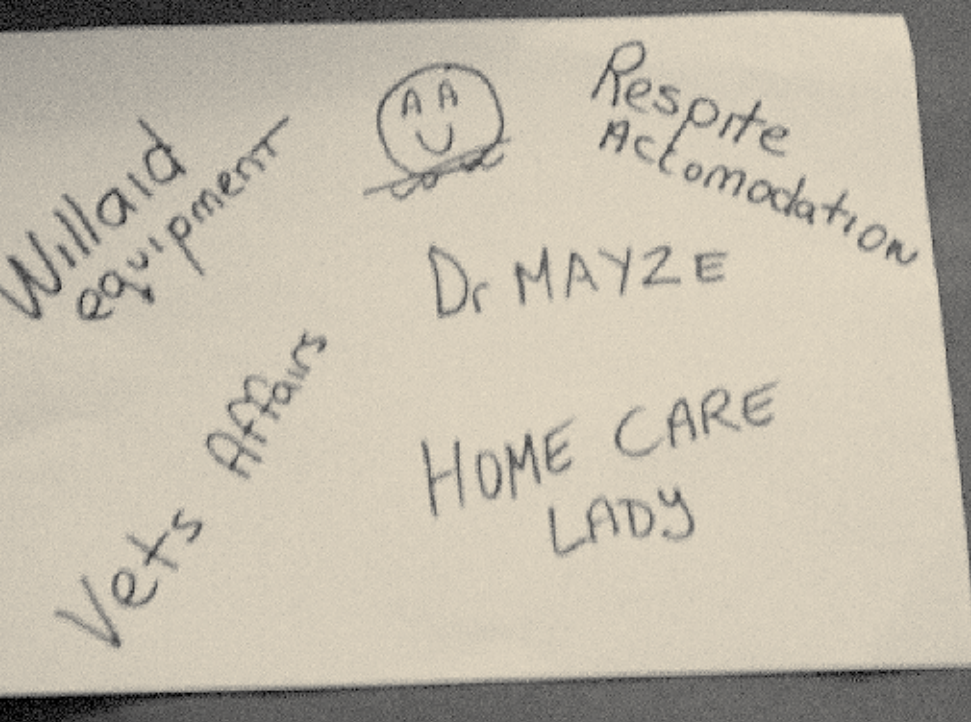
- **Faith communities –** were strongly (though not universally) present for carers of faith, providing practical, emotional and spiritual support.

- **Neighbours –** important role in keeping an eye on the dying person and communicating with the family and also, because they are close by, they can quickly respond to a problem. Sometimes it is not obvious that people are in the caring network until their help is needed: for example, when the power went out 'the people next door came and asked if there was anything they could do and they'd already rung the electricity provider to tell them that Mum was on oxygen and we needed power.'

- **Schools and clubs –** play a part, as do groups who share hobbies and regular social activities where people are visible and known. Some people had extensive networks due to their involvement in large organisations such as the Scouts, the Rural Fire Service, or the Gay and Lesbian community. These organisations provided direct help but could also raise funds to cover costs, provide for the funeral, or give the dying person a holiday.

- **Local retailers (chemists, grocers and newsagents) –** delivering necessities and also donating a range of products. One carer liked to reciprocate with a batch of biscuits.

- **Members of support organisations for carers or people with a particular illness –** could provide the reassurance that comes with the sharing of a common bond, but also they were particularly valuable sources of information about services. Indeed, carers received information from many different people within the wider community and that was one of the major advantages of having a wide network.

People like at the doctor's surgery – I practically lived there – and they were the ones that you shared your life with and they all became personal friends.

Carer 26, urban 4

Impact of death

Formal service providers were seen as a part of the community supporting the carer, but the abrupt end to the relationship when the person died could be a shock. This is because such sudden disconnections are at odds with the understanding of community. In a minority of cases the relationships with formal service providers continued, with one developing into a close friendship.

Outcomes

The data identified a number of positive outcomes:

Changing attitudes – Support from any segment of the community could change the carer's attitude to the local area. Some carers discovered for the first time that they did indeed have a community and resolved to remain in the area.

Developing connections – The strengthening of connections or the creating of direct connections to outer network members surprised some carers. For example, 'people like at the doctor's surgery – I practically lived there – and they were the ones that you shared your life with and they all became personal friends' (Carer 26, urban 4).

Giving back – After the person had died, some carers wanted to give back to the community by supporting community activities and local businesses, and helping other carers or those who were grieving: one even completed a pastoral care course.

Once relationship building is accepted as an important aspect of caring there is the potential for a range of people to become involved in the caring network and to develop a good collaboration between paid care workers, volunteers and informal carers. This stage has the potential for growing social capital. The strong relationships formed through caring can potentially be mobilised for other activities. The network not only supports the care recipient and the carer, but also provides the opportunity for community members to become familiar with the nature of caring. Thus there emerges a community development aspect to caring.

Theme five: Place

Carers described the importance both of their own and the dying person's relationship to place. This togetherness was developed through sharing space, for example building and renovating, gardening, going fishing, cooking and eating, celebrating important occasions around the barbecue or the pool. They described enthusiastically and with great feeling how these shared spaces were symbolised as artefacts (paintings, drawings, photographs) or had drawn them into memorial rituals (such as the scattering of ashes) and gatherings for anniversaries and reunions.

Creating connections through place
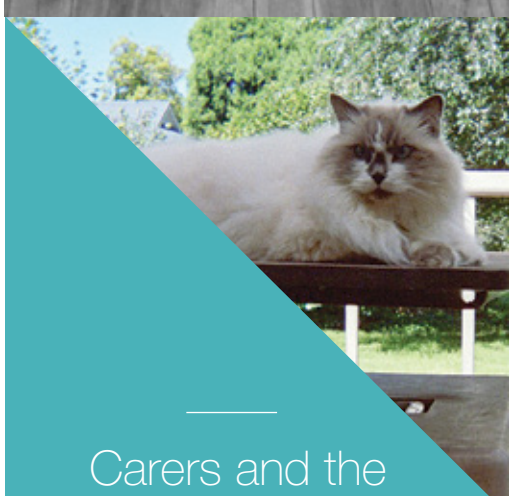
The natural world – Carers emphasised the important of a connection to nature, either through creating and nurturing a garden, caring for and protecting wild spaces, or nurturing the spirit through being in, engaging with, and reflecting on wild nature (observing creatures in the wild, gazing at a sunset or a breathtaking view).

Proximity to important objects, places and people – Carers and the dying maintained their identity and sense of belonging by knowing where they were in relation to everything they love. Some felt the need to mark the passage of time by being able to see a clock.

Cultural – Connections to local and current (churches, communities, clubs, neighbourhoods) or places of the mind and the heart (distant countries of origin, ideological and political affiliations). There were many examples of the comfort derived from being in the places people know best – home; community; familiar landscapes. Through all these connections, the carers and dying person could maintain their old identities. They were still treated as 'Anne' and 'John' by their friends and could avoid being swallowed up by their current roles.

Carers and the dying maintained their identity and sense of belonging by knowing where they were in relation to everything they love.

Constructing a caring space

Carers were aware of the need to create caring spaces through an active, thoughtful and practical approach, and went to considerable trouble to ensure that homes were set up efficiently.

It was recognised that an effective caring environment didn't just happen by accident. The caring space was seen as having a physical, emotional and aesthetic dimension – as being a space where the primacy of providing for the physical needs (hospital beds, hoists, wheelchairs), and the comfort and safety of the dying person (and the caring network) went hand in hand with providing hospitality and maintaining connections with family and friends. How the dying person experienced the space, how comfortable they were in it, what they looked at and could continue to share in the home were of great significance.

The spaces that worked best for formal and informal carers and for the dying, were those where physical needs (lifting, medicating, bathing, dressing, feeding) could be met with ease and privacy, as well as providing a sense of connection and continuity in household activities. This ensured people didn't feel or become isolated from family life and could continue to contribute and share happy times. Modifications were common (and sometimes costly) – bathroom renovations, ramps, widening of doorways, external access, driveways for vans and buses – as was the repurposing of rooms. Living rooms became bedrooms, sunrooms command centres and verandas set up with day beds and gathering spaces for visitors.

The common theme in all caring households was the busy-ness of caring. The need to accommodate much larger cohorts of people on a daily basis, attend to rapidly changing physical and emotional needs and maintain all aspects of life (domestic and communal) under one roof.

Respite spaces

Respite spaces were a focal point in the majority of caring households. Often this was separate to the formal caring spaces – a kitchen, outdoor table, sunroom or a veranda were used as spaces where carers and caring networks could gather to rest, plan, share feelings and nourish one another physically and emotionally, sharing food, and perhaps a glass of champagne along with the stories.

This idea of respite spaces is quite different from a service provision orientation where, usually, the dying person would be transferred to a 'facility' in order that the carer gets respite. Almost universally our data showed that the service provision respite spaces were disliked and unhelpful.

> Hannah used to come practically every afternoon and bring the champagne. Which was really nice because at the end of the day, you know, it was really heavy going. He was pretty sick so that was another icebreaker – the champagne. And then Kent would rock up with the afternoon tea or the girls would come round and take me out for coffee.
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> *Focus group 12, urban 2*

Creative space

This research recognises that caring for the dying can be creative work – work that requires space for flexibility and new ways of thinking to emerge. In describing the spaces where people care as 'creative space' we are referring to an imaginative and emotional landscape where transformative growth can occur, and where transitions that transcend fear, anxiety and personal limitations are possible.

Carers may stumble into that creative landscape accidentally or go there intuitively, but they are also often guided there by the dying person, by other members of the caring network, and by skilled professionals. When carers and carer networks find (and are given) the space to be creative in their work, it is then that they are most likely to receive the 'gifts' of discovery, understanding, and shared knowledge – about death and dying and about each other – that emerge from the fruits of their labour (Yardley, 2011).

The creative and collaborative work of carers and the dying includes the making of artefacts which record and mark their shared journey – stories, paintings, drawings, and photographs, and the creation of rituals such as funeral services, memorial events and reunions. All these activities communicate insights gained and map the journey undertaken. Through creativity, the 'everyday' world and sheer hard work of caring can become part of a culture shared by the caring network and the community in which they live (Csordas, 1994; Yardley, 2004).

Gone fishing

Andy loved his fly fishing – his fishing rods were pretty important to him. He was enormously interested in, and dedicated to, 'real fishing' – and it needs to be understood that we're talking about freshwater fishing here. We're not talking about deep water fishing or getting lost at sea or anything like that. It's a carry over from the English tradition of fishing for salmon and trout, and Andy was a master at that.

Andy and his nephew had a great fishing trip to Kakadu the year he died. They had been wanting to go for a while and he was beginning to physically go downhill so they said, "If we're doing this, we're going to have to do it now".

They went in the massive Northern Territory wet season. It was a fabulous trip for them. They did some fishing and they did trips in and around Darwin and Kakadu – something they both really wanted to do. The whole trip had to be organised very quickly. He really collapsed after that – by the time he came home he had really started to deteriorate.

We scattered his ashes in the Murrumbidgee. I'd never fished in the spot he chose so I went down a couple of days earlier to get to the spot. It's very hard to get to, on that back road that runs from Canberra to Adaminaby – absolutely in the middle of nowhere.

I had promised him I wouldn't throw his ashes in until I caught a fish – until he 'let me' catch a fish! But I couldn't catch a fish the whole time I was down there.

Some people wouldn't care what you did with them after they die but other people are very particular about where their ashes should be or where they're going to be buried.

Andy and his brother had fished in that particular place. Andy's brother died in May of 2005, and Andy died in July. Mike was cremated as well so we decided that their ashes could both be scattered in the same place on the same day, and that's what happened with the proviso from Andy that Mike went first, so 'I can jump on him'.

We all spent the weekend in Canberra. It was a special family thing. We scattered the ashes on the Saturday, and then went back to Canberra for a meal and then joined each other for breakfast the following day – a whole family get-together.

It was a really good day.

He was enormously interested in, and dedicated to, 'real fishing' – and it needs to be understood that we're talking about freshwater fishing here.

Discussion: Co-creating an ecology of care

Underpinning ethic of care

If we follow carefully what they say about their reasoning and expectations for undertaking a caring role, those who choose to care at home embark on their end-of-life caring journeys with an almost implicit acceptance of an ethic of care with regard to the dying person.

The terminally ill person is viewed, because of their circumstance, to be vulnerable, in a situation where agency cannot be maintained or wishes fully met without the intervention and care of family and friends. It is taken as a given, that an interdependence exists between the carer themselves, the dying person and others within their social and caring network.

What carer stories tell us is that whatever the relationship might have looked like before diagnosis, once the illness is known to be terminal, the dying person is seen as more vulnerable than others (including the carer), and that those who are less vulnerable have a duty and responsibility to step-up.

Traditionally, in caring theory, warm relationships are seen as desirable and necessary for quality caring. The focus is, ideally, on the person not on the problem (Noddings, 1984).

The ideal caring is 'an activity of relationship, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone' (Gilligan, 1982, p.62). Not to leave another person in a vulnerable position is one of the cornerstones in a 'caring rationality', a concept developed by Wærness (1984), emphasising the role of emotions in social care. Like Noddings and Gilligan, Wærness emphasised the value of personal experience that should provide a guide for the best caring, not the scientific rationality of what we today would call evidence-based practice. (Commonwealth of Australia, 2010).

This ethic of care is relevant to both informal and formal carers. The rewards for the care worker are a positive feeling and a sense of meaning in their work (Karner, 1998). However, Tronto (1993) is concerned about the exhaustion syndromes among care workers due to too many and contradictory demands directed towards them. Tronto points out the risks with building relationships in caring and raises questions about how much to disregard one's own needs to being attentive to the care recipient and how to judge if those needs are genuine.

To address the tension between the traditional ethic of care and the concern for care workers, Kittay et al. (2005) question the traditional distinction between dependency and independence. They see dependence as a central feature of human life and focus on relationships and interdependence rather than independence. Instead of seeing dependence as a burden they suggest that dependency is 'an opportunity for flourishing.' Instead of being a potential source of conflict or a burden the dependent person can offer an 'occasion for forming deep and abiding bonds of love and friendship.' A fair, just and caring organization of care labour can offer 'the opportunity to create societies in which trust, real fellowship, and real difference can co-exist.'

Language power and practicality

There are a number of interconnected discourses at play in an end-of-life care environment as role positions are constructed and relationships and care needs change and develop. Our participant groups moved, at times effortlessly, between a formal, service provider discourse, a community discourse around place and identity or a transformational discourse around death and dying depending on the aspect of practical care, personal reflection or care environment factors they needed to communicate.

The terminally ill person is…in a situation where agency cannot be maintained or wishes fully met without the intervention and care of family and friends.

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Changing available language changes available practices and conceptual boundaries as well, opening up the possibility of sharing a skill and knowledge set both necessary and desirable to informal caring networks.

Carers wanted people with expertise around – the voice of authority to validate what they were doing. They might not have wanted someone telling them what to do, but they did want technical advice: this is how to inject; medicate; turn; bath; cope with seizure etc.

They did want validation for what they had already done; and recognition of the expertise that they had to share – with each other, their communities and with service providers. They were saying, 'Don't butt out – stay present – share expertise – it's a two way street'.

Carers want positive input

'What would it be helpful for me to tell you?' 'This is some of what you might need to look out for.' They want productive, informative, practical support.

Tensions arose when social constructions of 'professional', 'carer' and 'patient' got in the way of relationships – particularly when relations of power were negative and proscriptive, and systems inflexible and hierarchical. Professionals sometimes had a tendency to forget that respect for expertise is conferred and earned not a given.

Carers commonly expressed concepts of a shared journey, of a person 'dying well', and of a sense of collective achievement. These achievements had been earned through constancy, reciprocity, dedication and sheer doggedness in keeping faith with a dying persons wish to die in their own home with everything they loved around them.

There was no equivocation about what dying 'well' meant. It's not necessarily being pain free, completely at peace, without fear, anxiety or regret – for the dying person or the carer – but at home, with a sense of purpose in a collective human task, surrounded by the loved and the known so that dying people retain their identities by staying connected to the people and places that are meaningful for them.

Ecology of care

We found that the dying person and their caring networks exist within a complex web of social-environmental relationships where knowledge, skills, values, attitudes and beliefs of network members are influenced by factors such as: existing relationships with people and place; formal and informal organisations and groups to which they already belong; the nature of the communities in which they live; social norms and expectations of the groups and cultures with which they identify; experiences and knowledge of health services and other social support organisations (see also Huang, 2014).

While this web of already existing relationships affects a network's ability to come together in the first place, we also found that this was a two-way street.

Members of networks were affected individually, collectively and communally. No-one and no environment remained the same, so this web of relationships and the knowledge, skills, values, attitudes and beliefs within the web also changed. This ecological view of caring asks that we put our understanding of these interrelationships first and foremost (Richard et al., 2011).

An ecological view also asks that we see 'home' not as an isolated place where a dying person and their carer may live, but as a place which exists with/in a larger environment: the block or garden, the street, the village, the neighbourhood. These are dynamic and inhabited with people, trees, flowers, creatures, sounds, smells, and sensations such as the sun on your skin. These places are not passive.

The stories from our participants showed that they were actively supportive of caring networks in terms of both enabling and maintaining end-of-life care. Put simply, environments impact relationships and our ability to both care and be cared for. This is important as the multitude of relationships between people and between people and their places clearly have effects on the dying person, the network members' and the broader community's wellbeing and effectiveness.

An ecological, or social ecological, approach to health promotion is gaining some prominence (see for e.g. Simons-Morton et al., 2012; Richard et al., 2011; Lang & Raynor, 2012). What this particular research adds is evidence regarding how feelings of belonging and attachment to place affect both the dying person's and the caring networks ability to come together to care. The stories from our participants show 'cycles of mutual influence' (Stokols, 1996, p.286) where both place and social relationships co-created spaces in which to care, and to care well. The environment, in this case the home, actively enabled an ecology of care to develop and be maintained over time.

> *I'd do it again. I'd do it again for Mum, but in saying that I also learned a lot about myself. It improved my relationship with my brother. It gave me insight into Alzheimer's, into the disease. It allowed me to come in contact with people I would never have come in contact with – like Covenant Care people. So I feel very blessed in that I've had that opportunity to travel that road. I feel very blessed that Mum died at home and died in her own surroundings and with people she loved. I feel very humbled by it all.*
>
> *Carer 10, urban 4*

Compassionate communities

In Kellehear's vision for compassionate communities, community development and community capacity building can enhance the ability for knowledge about end-of-life care to be developed and sustained within the community. This then enables communities to utilise support systems, problem solve, make decisions, and communicate and act more effectively when someone in their community is dying (Kellehear, 2005).

There were glimpses of compassionate communities; in some cases local people not closely connected to the dying person stepped up to offer help. We call these glimpses because they were not widespread. Only half the networks included community members other than neighbours or formal service providers. In most cases there was a strong prior association, for example, a church, club or community group that the dying person or carer had been involved with.

Ways to create compassionate communities

These glimpses suggest that there is a huge potential for mobilising help from local people, and that everyday kindness is not uncommon. What is lacking is the knowledge and acceptance that it is the role of the local community to offer help. The norms of respecting privacy seem to be much stronger than the norms of kindness. The way forward may include the following:

- **Mediators and facilitators –** people who are close enough to the carer and the dying person to understand their needs and preferences, but also able to interact widely in the community.

- **Social change –** this is needed so that communities can accept that they do have an important role at end of life, a role that will ultimately strengthen both the community's capacity to care and the social capital available to them to invest in other developments.

When palliative care practice focuses primarily on the needs of the dying person and secondarily on the needs of their principal carers, there is a tension whereby increasing the quality of life of one can be detrimental to the other. The effective implementation of health promoting palliative care (HPPC) policy dissolves this tension by providing a wider network of individuals and organisations in the community to share the work of caring.

We found in the first stage of this research that people within the system would like to engage with the HPPC approach. Although HPPC is prescribed throughout state and national palliative care policies in Australia and we found in the first stage of this research that people within the system would like to

engage with that approach, health personnel are uncertain about how to engage with HPPC and perceive a number of barriers (Horsfall et. al. 2014). Also recent state and federal initiatives in Advance Care Plans are important for dying people to take some control by registering their wishes about how and where to be cared for at end of life, but recognition, acknowledgement and support by all parts of the community and services are necessary for those plans to eventuate (Horsfall et al. 2014).

Transformation discourse

Caring at end of life has the potential to make transformational changes in people and their relationships. These changes are not just a matter of degree, such as an increase in the number or strength of relationships, but rather that people now experience themselves, and others as fundamentally changed. They have become stronger, braver, more open people.

Respondents talked about being able to open their hearts to others in a way they had not previously had the capacity to do, and of being "free to share even more of vulnerable self". Respect was a key indicator of the changes in relationships with others. Parents came to recognise that their adult children were indeed adults who could step up and take charge in difficult situations and in ways they would never have expected. It was an opportunity to see others displaying compassion and patience often absent from everyday life.

The intensity that comes with dealing with life and death matters was identified as one important catalyst for the change. Another was the opportunity caring presented for people to step forward, face their fears, and choose to contribute, even though they do have the option to avoid this life challenge.

Conclusion...

This report is the culmination of six years of social research in NSW and the ACT.

We began with the aim of further developing knowledge and understanding of how informal networks care at the end of life. We also wanted to identify the impact this caring had on both the informal and formal caring networks. It was our intention that these in-depth insights would inform public health policies and palliative care practices in Australia. Principally, it would add further understanding to the way public health approaches to palliative care translate to the practice of end-of-life care within the community.

This report has described four key themes: networks, service providers and service networks, death literacy and place. These themes come together under the term 'co-creating an ecology of care.' This concept puts place and environment and people's attachment to place, centre stage in end-of-life care. This includes trust, shared norms, collective action and social agency.

For participants in this research the act of caring at end of life can be described as dynamic social action. Carers navigated the health system while actively learning about end-of-life caring. They faced and overcame significant barriers from the health system and service providers. Further, they actively created a network of support that enabled end-of-life care in the home.

These formal and informal care networks were seen as essential for home-based end-of-life care, performing numerous functions from practical support through to emotional support and transmission of knowledge (i.e. death education). Networks also moderated or acted as a protective barrier to the stress experienced by primary carers and those in the wider network. This was especially true when the care network included a person who had experience with end-of-life caring.

Interestingly, health professionals featured in only half of the participating care networks. Despite this, service providers were considered an essential part of the care that is provided to the dying person and carers valued their expertise, particularly in pain management and the provision of home-based care equipment.

Service providers were, however, a primary source of stress and anxiety to home-based carers. Tensions arose when the social constructions of 'professional', 'carer' and 'patient' got in the way of relationships between the service provider and the carer and the care network. The most positive relationships between carers and service providers were characterised by the service provider 'fitting in' with the informal care network and embracing the existing ethos of the household.
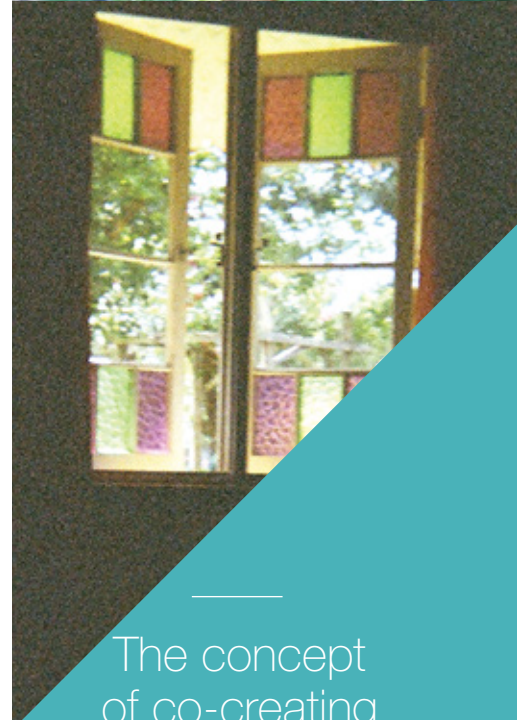
The concept of co-creating an ecology of care puts place and environment and people's attachment to place, centre stage in end-of-life care.

Future directions

Stage 1 of this research, which was from the service provider perspective, found that informal caring networks were essential in supporting someone to die at home.

Stages 2, 3 and 4 from the community and carers' perspectives, found that formal networks were similarly essential in supporting someone to be cared for at home.

While we have discussed the concept of *the caring network,* in reality this is comprised of *two separate networks:* the formal and informal with different cultures of practice, different languages and different motivations for providing care; and different priorities and goals.

We are, as a result, left with two important questions:

'How can health systems more fully support informal caring networks?'

'How can formal and informal networks work together in co-creating an ecology of care?'

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Acts

Consent to Medical Treatment and Palliative Care Act 1995 (SA)
Guardianship Act 1987 (NSW)
Guardianship and Administration Act 1986 (Vic)
Guardianship and Administration Act 1995 (Tas)
Guardianship and Administration Act 1990 (WA)
Health Care Directives Act 1992 (Canada)
Medical Treatment Act 1988 (Vic)
Medical Treatment Act 1994 (ACT)
Mental Health Act 1986 (Vic)
Natural Death Act 1988 (NT)
Powers of Attorney Act 1998 (Qld) Appendices

Appendices

Participant information sheet

Caring at End of Life Project
Participant Information Sheet (General)

Who is carrying out the study?
The project is being conducted by Dr Debbie Horsfall and Assoc. Prof. Rosemary Leonard from the University of Western Sydney, Dr. John Rosenberg from Calvary Centre for Palliative Care Research and Gillian Batt from Cancer Council NSW. This project is funded by the Australian Research Council in partnership with Cancer Council NSW

Carers past and present, their supporters and services providers in the end of life care sector are invited to participate in a study conducted by Dr Debbie Horsfall, School of Social Sciences, University of Western Sydney.

What is the study about?
The aim of this research is to provide in-depth understandings of informal and formal caring networks when someone who is dying is being cared for at home. Informal networks are described as friends, family and neighbors while formal networks are provided by services through health professionals and volunteers.

We are interested in how these networks work together to enable caring in the home. The findings may be useful for other people who are caring, service providers as well as enabling organisations to better support carers and their networks.

If you are a carer, we will not be talking to you about the experience of caring, as such, but about the relationships and social (or community) networks that supported you while you care/d. We are also interested in how these friends, neighbours, family, work colleagues or people help out now and then. The type of things support networks do can include: picking the children up from school; popping in for a chat; mowing the lawn; doing the shopping; providing some 'time out' for the carer; ringing people up to see how they are going; organising projects and tasks that need to be done.

If you are a service provider, we are interested in how you work with and support informal care networks.

What does the study involve? This project has 4 stages

Stage 1. Service provider focus groups. Service providers will discuss their experience with informal networks, their perception of the nature, role and benefits/problems of informal care networks, and their current and/or potential role in assisting carers to establish and/or maintain informal care networks. The focus groups will last 2 hours and be audio taped and transcribed.

Stage 2. Interviews with Carers. Past and current carers will be interviewed exploring the nature and role of informal and formal support networks. Prior to the interview carer will be given 2-3 disposable cameras to take photos of the events and things that represent their experience of caring and draw a map of their support network. The interview will last 1-11/2 hours and be audio taped and transcribed.

Stage 3. Focus groups with caring networks. Carers will be given assistance from the RA to contact their self identified informal network. The aim of the focus group is for the social networks to respond to the photos and later develop a network map. In particular we are interested to discuss the effects on social networks and community building and their attitudes towards end of life care and dying at home. The focus groups lasting 2-3 hours will be audio taped and fully transcribed.

Stage 4. Interviews with the "outer networks". People who participate in the carer interview or focus group will be asked to circulate information to people in the outer-networks. Participants in the outer network will be each interviewed about the role they played in the caring network and the affects if any this network has made to their attitudes about death and dying. They will draw networks maps and be interviewed for approximately 30-45 minutes. Interviews are audio taped and fully transcribed.

How much time will the study take?
How much time the study takes is dependant on which stage of the project you are participating in, but this is between 2-3 hours.

Will the study benefit me?
The study will provide an opportunity to reflect on both the formal and informal caring experience and reconnect participants with people in care networks.

Will the study involve any discomfort for me?
It is not expected participating in the project will cause discomfort however a list of support services is attached to this information sheet.

How is this study being paid for?
The study is being sponsored by a ARC linkage Grant which is a funding partnership between the Australian Research Council and Cancer Council NSW.

Will anyone else know the results? How will the results be disseminated?
All aspects of the study, including results, will be confidential and only the researchers will have access to information on participants.

Can I withdraw from the study?
Participation is entirely voluntary: you are not obliged to be involved and - if you do participate - you can withdraw at any time without giving any reason and without any consequences.

Can I tell other people about the study?
Yes, you can tell other people about the study by providing them with the chief investigator's contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

What if I require further information?
When you have read this information, Dr Debbie Horsfall will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Niki Read on xxxxxxxx (n.read@uws.edu.au) or Kerrie Noonan on xxxxxxx (k.noonan@uws.edu.au)

What if I have a complaint?
This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is [enter approval number]

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form.

Caring at End of Life ARC Linkage project

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Invitation to take photos

Caring at End of Life Project
Research information for about taking photos and focus groups

Taking photos of caring experiences

1. You will be given disposable cameras, instructions and consent forms about the project for you and your support network. The cameras are for you and your support network to photograph what you think were significant tasks, events, people or experiences as you supported someone at the end of their life.

2. Over a period of 2 weeks, think about these caring tasks, events, people or experiences and take photos of them or something that represents that.

3. Make a list of the people in your care network and invite them to take photos of the things they did. It is important they have a read of the information, so give people the letter of invitation to support networks.

4. Make a date for the discussion group (about 3 weeks from receiving cameras; it can be in your home, day, evening or weekend). We will help you to do this.

5. Return the cameras to the research assistant for developing in time for the discussion group.

You and your support network may already have some photos taken at the time of caring which we encourage you to include in the research if you would like to.

What/who is the support network?

The support network will be those people you identify, and can be any person who has provided support to you and/or the person you cared for. Support networks can be social or from your community and can include friends, neighbours, family, work colleagues or people that help out now and then. The type of things support networks may have done to assist you include: picking the children up from school; popping in for a chat; mowing the lawn; doing the shopping; providing some 'time out' for the carer; ringing people up to see how they were going; organising projects and tasks that needed to be done. The research team can assist you in identifying who your support network was made up of and in coordinating them for the research.

What if I don't want to do it, or change my mind?

It is entirely up to you whether or not you participate in this research. If you do decide to be part of this research you may change your mind and withdraw from the research at any time during the project. You can talk to other people about this project if you wish and provide people with the contact details below if they would like further information.

Stage 2. Focus Group – gathering together to talk about the photos and caring

1. Invite members of your support network to the discussion group. It doesn't matter if they have or have not taken photos.

2. The focus group will be in your home at a time that suits you; the researchers will organise this in consultation with you. Your group meeting will last approximately three hours and will be run by one of the researchers. This conversation will be recorded for research purposes. At the meeting, your photos will be on display and will be used as part of the discussion to see which images people thought were interesting and/or important. We will also have a cuppa and share some food which we will provide.

3. Permission for the researchers to use any of the photos will be sought from the support network.

4. The researchers will then ask people to draw 'network maps', which will help illustrate the relationships before and after you supported each other in caring for someone in the final stages of their lives.

On completion of the project, all participants will receive a summary of the research results, as well as a copy of photos taken for you to keep as a legacy of your time shared.

Support is available if the research affects you

We do not believe that being part of this project will cause you any distress. However, if you do become distressed, Kerrie Noonan, a qualified psychologist, is available for immediate support regarding the research (0439 040499). We will also provide you with a list of counselling services in your area.
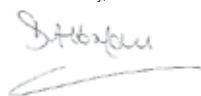
Protecting your privacy

We will ensure that anything said in the discussion group is treated confidentially to protect each participant's privacy. No real names will be used with the information we collect, in the final research report or any articles written on the research.

When you have read this information, we will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact:
• Research Assistants Niki Read n.read@uws.edu.au or Kerrie Noonan k.noonan@uws.edu.au

Yours faithfully,

Debbie Horsfall
University of Western Sydney

Note: This study has been approved by the University of Western Sydney Human Research Ethics Committee (H9255). If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome

Project information

Caring at End of Life project – Project information
Past and current carers

As someone who is currently caring, or who has previously cared for, someone dying at home, we would like to invite you to participate in a research project being undertaken by the University of Western Sydney, Calvary Centre for Palliative Care Research and the Cancer Council of NSW.
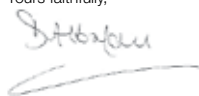
The project is about:
- How friends and family support each other when caring at home.
- What people do to support the carer at home and binging to life the everyday tasks of caring
- Allowing the community to be their own experts, to speak for themselves
- The effect of the experience of helping one another
- Understanding more about how formal and informal carers work together when care is being provided in the dying person's home.

The results of this study will be applied to creating better support for people who wish to die at home. It is entirely up to you whether or not you participate in this research.

When you have read this information, we will discuss it with you further and answer any questions you may have. We will also provide you with a more detailed information sheet about the project. If you would like to know more at any stage, please feel free to contact:
- Research Assistants Niki Read n.read@uws.edu.au or Kerrie Noonan k.noonan@uws.edu.au

Yours faithfully,

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Caring at End of Life ARC Linkage project

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Invitation to take photos

Caring at End of Life project
Invitation to take photos and use the cameras.

We invite you to take a photo now and then over the next few weeks of the things that you do while you care.

There is no right or wrong photo. If an image comes straight to mind we invite you to pick the camera up and take a photo right now! Sometimes acting on that impulse is important. You don't need to think too hard about this task. We are hoping you will capture the every day things that you do. We want to see what you want to show us. It may be a photo of a lawnmower, someone making a cup of tea, information brochures, the birds outside the window, people arriving to visit, a book you have lent.

If you need some prompts these questions might help you:

- What is it that you did today? Take a photo of that.
- What image could capture what you did?
- Who else if here and how did they help?
- What things did you use? Take a photo of them.
- Did someone help you? Take a photo of that.

Please make sure you have read the Information Sheet (attached) before you do take any photos. We will develop these photos and bring them to the interview to begin the discussion. If you take a photo of a person, the researchers can only use that photo if that person gives permission with a signed consent form.

The project is being conducted by Dr Debbie Horsfall and Assoc. Prof. Rosemary Leonard from the University of Western Sydney, Dr. John Rosenberg from Calvary Centre for Palliative Care Research and Gillian Batt from Cancer Council NSW. This project is funded by the Australian Research Council in partnership with Cancer Council NSW

Invitation to take photos

Information sheet for carers to keep with the disposable cameras
Caring at End of Life project
Invitation to take photos and use the cameras.

These disposable cameras are here for you to use as you help support (insert carers name). We invite you to take a photo now and then over the next few weeks of what you are doing to support (insert carer's name). Please feel reassured that (insert carer's name and insert dying persons' name) knows that you will be taking photos and is more than happy for you to do so.

There is no right or wrong photo. If an image comes straight to mind we invite you to pick the camera up and take a photo right now! Sometimes acting on that impulse is important. You don't need to think too hard about this task. We are hoping you will capture the every day things that you do. We want to see what you want to show us. It may be a photo of a lawnmower, someone making a cup of tea, information brochures, the birds outside the window, people arriving to visit, a book you have lent.

If you need some prompts these questions might help you:

What is it that you did to help today? Take a photo of that.
• What image could capture what you did?
• Who else if here and how did they help?
• What things did you use? Take a photo of them.
• Did you bring something with you? Take a photo of that.

Please make sure you have read the Information Sheet (attached) before you do take any photos.

We will develop these photos and they will be taken to a group meeting of (insert carers name) support network. They will be displayed at the beginning of the meeting and used to begin the discussion. The group will not necessarily know who took which photo. People at the meeting will be invited to take home any of the photos you would like at the end of the group meeting.

It may be that the people doing the study would like to use some of these photos in their reports or articles. If the photo has someone(s) from the network in it they will only use it if they get the permission of that person/people.

The project is being conducted by Dr Debbie Horsfall and Assoc. Prof. Rosemary Leonard from the University of Western Sydney, Dr. John Rosenberg from Calvary Centre for Palliative Care Research and Gillian Batt from Cancer Council NSW. This project is funded by the Australian Research Council in partnership with Cancer Council NSW

Invitation to take photos (Aboriginal people)

Information sheet for carers to keep with the disposable cameras, where the dying person does not wish to have their photo taken due to being an Aboriginal person, or who has not given consent.

Caring at End of Life project
Invitation to take photos and use the cameras

These disposable cameras are here for you to use as you help support (insert carers name). We invite you to take a photo now and then over the next few weeks of what you are doing to support (insert carer's name). Please feel reassured that (insert carer's name) knows that you will be taking photos and is more than happy for you to do so.

Please do not take photos of the person being cared for as they do not wish you to.

There is no right or wrong photo. If an image comes straight to mind we invite you to pick the camera up and take a photo right now! Sometimes acting on that impulse is important. You don't need to think too hard about this task. We are hoping you will capture the every day things that you do. We want to see what you want to show us. It may be a photo of a lawnmower, someone making a cup of tea, information brochures, the birds outside the window, people arriving to visit, a book you have lent.

If you need some prompts these questions might help you:

- What is it that you did to help today? Take a photo of that.
- What image could capture what you did?
- Who else if here and how did they help?
- What things did you use? Take a photo of them.
- Did you bring something with you? Take a photo of that.

Please make sure you have read the Information Sheet (attached) before you do take any photos.

We will develop these photos and they will be taken to a group meeting of (insert carers name) support network. They will be displayed at the beginning of the meeting and used to begin the discussion. The group will not necessarily know who took which photo. People at the meeting will be invited to take home any of the photos you would like at the end of the group meeting.

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10 Stage 3: Focus groups with current or past carers and their caring network – Focus Group Schedule

Photovoice

1. Welcomes and introductions. Brief description of the project and signing of consent forms.

2. People invited to view and informally discuss photo display. (This stage also includes the throwing away of any photos people do not wish to be used in future).

3. People chose 1 photo that is significant for them and give it a title and write it on the back.

4. Group discussion of photos (These questions to be used as prompts and guides).
- What do you think the photos 'say' overall?
- What do they say about community and social networks?
- What do they tell us about this experience and how we help each other?
- Would you like to show us the photo you chose and talk about the title you gave it?

Network mapping
Step 1. Social Networks form

1. The participant will have with them a pre-prepared form which lists people that the participant has identified as being part of the caring network when end of life caring began and their relationship to them i.e. friend, neighbour, tennis club, service provider etc. Ask the participant to indicate the strength of that relationship when caring began by ticking the corresponding box i.e. strong, medium, less of.

2. The back of the page has the same people listed and is relevant to the date of the interview. Invite the participant to add anyone to the list they now know as a result of doing the end of life care.

3. A box needs to be ticked for each person listed.

Step 2. social networks maps
Procedure

A. Brief the participants
- Describe the 2 different maps which will be created; before and after, identifying where the line between before and after may be. (Before: at the time they became a part of the support network. After: at the time of the focus group).
- Discuss the use of coloured texta and measure of relationship in this context
- Describe the mapping process; discuss the examples and the possible 'messiness' or 'chaos' of the process.

The colours used will represent:

              more of a relationship

              medium level relationship

              less of a relationship

The coloured lines represent the relationship which in this context is measured by
- Length of time knowing the person &/or
- Intensity of the exchanges between one and other &/or
- Type and variety of shared experiences

B. Doing the mapping

Before caring	After caring
• Ask each person to clearly write their first name on the page • Now ask each person in turn to draw a line to each other with an arrow indicating the direction of the relationship, using coloured texta to indicate the measure of the relationship before the caring began. There may be no lines to some people as they were unknown to each other before, there may be more lines to the carer at this stage	• Ask each person to clearly write their first name on a fresh sheet of paper • Ask each person to draw a line to the other people they know and now know, again using the colour of the texta to indicate the measure of the relationship after being involved in the care network • People may wish to add a person to the network that is not at the focus group, if so everyone is invited to draw on the measure of their relationship to these people as well

4. Network analysis: Bringing the maps to life

Display both maps side by side, either lay down on table, or hold up, or blue tac to walls/windows as appropriate.

The following will be used as prompts and guides for the analysis.

- What do you notice about your two pictures?
- Do you think your relationships have changed? If so how, in what ways?
- Do you feel any differently about this community now? If so in what ways?
- Do you think being part of this support network has had any impact on your relationships? If so in what ways?
- Has it changed the way you think about death and dying?
- Have you learnt anything by being part of this network? About caring at home? About services? About each other? About your community? Are you doing anything, or thinking of doing anything with this learning? What will you do/ could you do with this learning.
- What difference, if any, has this knowledge made to you?
- How did the network come together? Did it already exist in some ways? Did someone help mobilise/organise all these people? Who helped keep it going and how?
- Does/did this network have any connections to formal services in the community eg. Palliative care, local service groups (RSL) church?

Notes