

# Breaking the Silence



**Margaret Evans meets a woman who challenges the last taboo.**

**M**olly Carlile is a woman who doesn't mince her words. Take this for example: "We talk about the quality and quantity of our orgasms in the pub with our friends. We talk to our kids about drugs and alcohol, stranger danger and safe sex. We talk openly about religion, politics and world events. No longer is any subject taboo. Except one."

And in case you're in any doubt that one taboo subject is death, Carlile has taken it upon herself to change this situation, with such success that she is now widely known as "the Deathtalker". A qualified nurse, Reiki master, counsellor and manager of the North and West Metropolitan Region of Palliative Care Victoria, she is well placed to speak with both authority and compassion on this subject we as a society continue to shun.

Carlile believes that we avoid the subject of death because "we see ourselves as immortal. We live in a bubble of denial, hoping that if we don't think or talk about death, we can avoid it." The result, she believes, is that when we are confronted with death, we are poorly informed and badly prepared.

But things are slowly changing with a noticeable opening up of this closed off area in just the last 12 to 18 months, says Carlile. "I've done so many more radio and TV appearances that wouldn't have happened five years ago. I don't think people are any less fearful, but we're more inclined to explore taboo subjects than before."

This month, she is bringing her message, sure to be delivered in her characteristic "no holds barred" style, to Perth for the first time, delivering a keynote speech at the Inaugural SolarisCare Symposium, *Back to the Future: Integrating Complementary Approaches into Clinical Practice to Promote Wellness*. The symposium has been organised as part of the SolarisCare Foundation's 10th anniversary celebrations. Other keynote speakers on September 16 at the UWA Club in Crawley will be Professor Marc Cohen of RMIT and Professor Jane Maher of Macmillan Cancer Support in London.

It's her work with dying and grieving people for over 20 years, since taking the decision to specialise in palliative care every early in her career, that has led Carlile to sense the need for a catalyst to start a necessary conversation. "As a natural evolution from my clinical work, I became aware that children were very poorly prepared for death in their families or school communities. And adults were very poorly prepared to have conversations about death and dying with each other and with their children.

"So my whole career has been built about trying to get people to have

versations and talk about things they are fearful of because, generally, a lot of conversations are grounded in myth rather than reality.

"Once people have had those conversations they can actually get on with the living part."

Molly Carlile's determination to fully reach out to end our self imposed suffering has led her in a new direction, exploring how the arts can be used to further the community conversation about death and dying. In 2009, she travelled to the United States, the UK and Ireland on a Churchill Fellowship to see how those societies addressed similar issues within the framework of the arts.

An inveterate seeker of new opportunities, she has also turned her hand to writing books for children and young adults, including *Jelly Bean's Secret* and *Sometimes Life Sucks*. Most recently, she's ventured into playwriting, collaborating with celebrated playwright Simon Hopwood on *Four Funerals in One*

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**"Once people have had those conversations they can actually get on with the living part." - Molly Carlile**

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ty. She will chair the forum discussion following the WA premiere of the play at the nearby Octagon Theatre, also on September 16.

As a society, we handle the whole issue of death "very poorly", she believes. The important limitation is our fixation with "battle language".

"In terms of people who have a terminal diagnosis, the major barrier they face is being able to talk about it in their family and social network because everyone keeps pushing them to 'battle' their way through it.

"I find the whole use of language around death terribly frustrating. We're always talking about the battle with cancer, the battle with dementia, or the battle with heart disease. It denies the opportunity to accept what's happened.

"It's not a case of someone not fighting hard enough. When you hear or see reports of death in the media, they always say 'died after a long and courageous

fight' with whatever it is. It just reinforces subliminally for everyone else that they weren't strong enough or persistent enough in that fight. That's the insinuation that comes from that battle language."

Says Carlile, people who have a terminal diagnosis "can only do what they can do." In focusing on the fight against illness, we are subtly forcing patients to

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**'The Deathtalker sees everyday life as providing golden opportunities to break the code of silence, starting with our children.'**

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"persist with pointless and uncomfortable treatments or even ones that make them feel more sick just to make their families feel they are still fighting."

In contrast to a Buddhist perspective that recognises the continuum of life in which death is accepted as the end of the cycle before renewal, an approach that is both more pragmatic and yet deeply compassionate, a Western society largely suffers in silence and denial.

It's a disconnect Molly Carlile sees all too often: "It's because we don't have those conversations until we're at this crisis point, at a time when people are very vulnerable, we are in protection mode, both of ourselves and the people around us. We think we protect them by not talking about the inevitability of the death that's coming."

On the other hand, if we were more comfortable in talking about death and "had had those conversations before anyone was sick and therefore it was seen

as a normal part of the human existence, we wouldn't have those disconnects at the point when someone is really needing to say things," she says.

The inability to truly express their feelings for fear of hurting their family or sensing their disappointment if they are seen to be giving up on "the battle", often denies the patient the chance to enjoy the last few months of their life.

"They don't get to say 'I love you' or 'I really want to die at home' or 'I don't want to die at home'. They don't get to take control back of their own life. They don't get to retain control of their life because at that stage they're at the mercy of the system and the people around them.

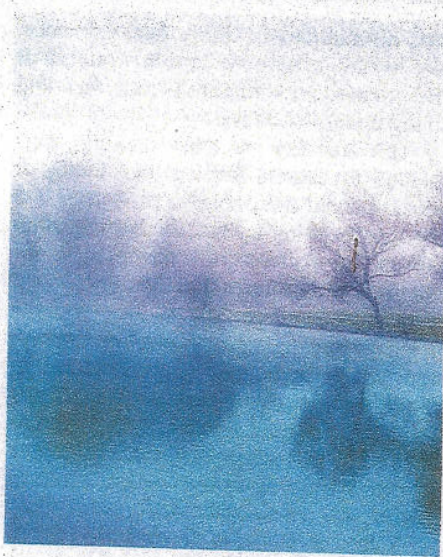
"Often the people around are just as scared - of how they're going to be able to cope with caring and scared of what might happen afterwards. But they can't talk about it either because they don't want the person who is sick to think they have given up on them."

The Deathtalker sees everyday life as providing golden opportunities to break the code of silence, starting with our children.

She often uses the example of nature, such as seeing a dead bird when out on a walk with the kids. "Don't just walk past it or kick it into the gutter. Stop, pick up a stick, give it a poke, ask the child what's the difference between this bird and that bird over there that's pecking on the ground or that bird that's flying.

"Just start the conversation simply by taking notice of what's happening around you in nature."

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Teachers, people who run community groups and parents are well represented in audiences for *Four Funerals in One Day*. Parents, in particular, feel ill equipped to have conversations about death with their children because they don't know how they feel about their own death, says Carlile.

"So when their kids ask them confronting questions, they change the subject. Or if something happens in a school community, rather than everyone sitting down and talking about it, they dive into the ritual and think that's dealing with it. It's important but it's just one part."

As a nurse, energy worker and administrator now turned writer, Molly Carlile is delighted that the play has created great interest all around the country.

"The fact that it stands alone as a performance piece is really important. Even though it has very clear messages and raises a number of quite confronting issues including euthanasia, that's what gets people thinking and what starts the conversations happening. That's the whole point of it really."

Her ability to tailor her message to vastly differing audiences was borne out the day before our interview when she gave a presentation to the Grand Round, a gathering of 250 people, all senior consultants, at Austin Health, one of the largest tertiary health services in Victoria. Her subject was how they approach the subject of death, particularly how their own view of death colours their clinical practice and their relationships with their patients.

"I was very controversial," says Carlile. "I told them you make excuses all the time about not talking about death with patients because you don't want

to upset them. But really it's not about the patient at all, it's about you feeling uncomfortable, about you not having thought about your own death and the implications of that, and so you use the patient's emotional wellbeing as a cop out."

Despite – or because of – her "full on" approach, the feedback was extraordinary. "People were coming from the oncology and cardiology and respiratory units asking me to come and talk to their junior doctors." It seems the message has been received that "we don't do this well and we need to start having these conversations".

The medical profession is under pressure from society itself to become more open and willing to engage in this previously closed off domain. Carlile partly attributes the greater openness to her message that she's noticed in the last year and a half to people's increasing sense of empowerment. While our ageing population is sure to be a factor, she believes people are now demanding more information from the health system. It's an approach at the heart of holistic medicine, where the individual achieves empowerment over all aspects of their health through greater awareness and a willingness to take more responsibility – to become masters of their own wellness.

The holistic awareness that nothing exists in isolation, in fact that everything is interconnected, is a key part of Carlile's message to senior consultants.

"I encourage them to see the whole relationship between them as a person, as a clinician, their profession, their community and the wider society is all interdependent. It's not until one component of that whole says, 'Hey, we're not doing this well and we need to change it' that the others will start to become important. That change has to come from somewhere. They can't wait for society's attitudes to change, they have to start with themselves and build it from there."

Just as challenging is her advice that a notoriously cerebral profession "moves from the head space into the heart space". "I say to doctors you're in your head space all the time. You have to move from the head to the heart if you're going to have a relationship with someone that's meaningful."

Our conversation over, it's time for this hyperenergetic communicator to pack her bags for a holiday in Thailand. She laughs off my comment that she's probably earned the rest with, "I'm not going to be lying on my deathbed saying I didn't make a difference." Clearly, that's not going to be the case. ●