

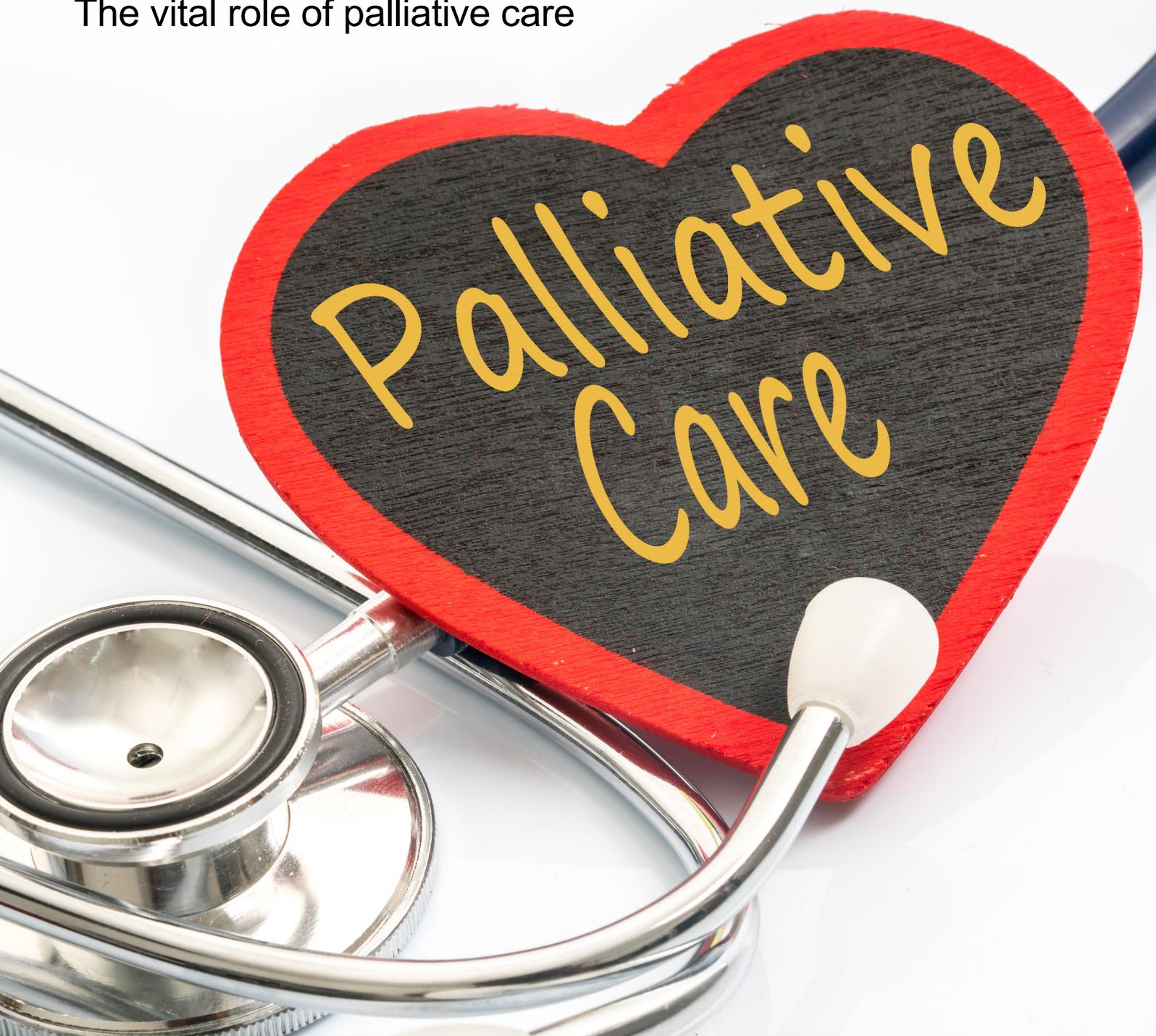
CHANGES

ANNUAL NEWSLETTER OF THE
National Association for Loss & Grief (NSW) Inc

NALAG
2019

A Good Death

The vital role of palliative care



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EDITORIAL

Jen Cowley OAM, is an award-winning former journalist and editor and a published author who has travelled Australia and the world pursuing her twin passions of community development and storytelling. Jen is Deputy President of NALAG, and is the author of *Grandpa's Hat* – a children's book about loss and grief, written as a therapeutic tool for healing after her own personal losses, with all proceeds directed to supporting the work of NALAG.

A good death: can there be such a thing? Anyone who has ever watched helplessly while a loved one dies a "bad" death will know the answer to that question is an unequivocal "yes".

What makes a good death? The jury has been and will continue to be out for some time on this, given the end-of-life journey is the ultimate personal voyage and does not come with a manual or a one-size-fits-all experience that can be reduced to a handy ready-reference of dot-point "how to-s".

But it's safe to venture that for most people, a "good" death is as pain-free and gentle as possible. To die without, or with minimal, distress or suffering, in the company of family and carers and in harmony with one's wishes and cultural considerations is what we hope for in a physical world where death is life's only certainty.

That's where palliative care comes in. As society moves towards a greater understanding and more open and honest discussion of death and dying, a groundswell of support for the provision of palliative care services – both formal and informal – is welcome if not overdue.

We still have some way to go to bring our collective personal lived experience and

learning – and the growing imperative of personal choice – into line with the "systems" that continue to govern death, dying and all it entails.

To this end, this edition of NALAG's annual magazine, *Changes*, is devoted largely to the discussion of palliative care from a number of professional and personal perspectives.

One of the common and recurring threads that runs through much of these considered perspectives is the need to continue to openly and honestly discuss death and dying in order that we can best build a more compassionate and accommodating network of support for individuals coming to the end of their lives, and their families.

To die without, or with minimal, distress or suffering, in the company of family and carers and in harmony with one's wishes and cultural considerations is what we hope for in a physical world where death is life's only certainty.

It helps not one iota that there persists a default to using euphemisms to address what we believe, mistakenly it could be argued, is a subject about which people are loathe to talk openly. The use of terms such as the omnipresent "passed away/on" are at best unhelpful, at

worst destructive. This is particularly true of the confusion these euphemisms create for children or people living with dementia or intellectual disability, for whom the cognitive capacity for abstract thought is not yet developed or is limited.

Using euphemisms is almost always a well-intentioned attempt to lessen the impact of or in some way protect ourselves and others from the often brutal and always final reality of death and dying. This is not necessarily and not always a problem on a personal individual basis, but there is an increasing body of evidence, anecdotal and qualified, to suggest that while ever service providers, the media, and those working in the "death system" remain squeamish about open discussion and the words "die, dead, death and dying", the road to personal choice in end-of-life decisions remains rocky.

As NALAG's clinical manager Dr Kerrie Noonan commented, "Perhaps one of the litmus tests for how far we've come is when people start using the terms "died" and "dead"."

On a personal note, I've been both cursed and blessed with a variety of experiences with the deaths of loved ones – unfortunate to have.

So if there is indeed such a thing as a good death, it is largely the product of equitable and flexible access to palliative care. To those at the front line of the fight for adequate and continuing resources for compassionate and informed palliative care services, we salute you. And we support you.

Q&A

with

Dr Kerrie Noonan

DYING TO KNOW

The importance of death literacy



DR KERRIE NOONAN has devoted much of her life so far to helping create a more “death literate” society. Kerrie spoke with Jen Cowley about her new role as clinical manager for NALAG, and her passion for building a more compassionate, whole-of-community approach to death, dying and bereavement.

You are certainly no stranger to NALAG – how did you first become involved?

I began my career as a bereavement coordinator with a community palliative care service, which is how I first came to be involved with NALAG in the '90s. I began working with particularly suicide bereavement at the same time as doing palliative care work.

I was on the board of NALAG for ten years, so this position of clinical manager with the organisation is a good fit. For the past ten years I've been running national events and

campaigns around loss and grief so this role combines a number of those skills.

What first piqued your interest in getting into this specific area of psychology?

I didn't set out to be a psychologist. I started volunteering for Camp Quality when I was 17, and then when I was at uni I volunteered for a program called Rainbows (the precursor to loss and grief program Seasons for Healing). As young volunteers, we went to funerals and hospitals and we spent time with dying children and their parents and we saw people die. And when I look around now, many of those formerly young people have gone on to careers in that space – nurses, doctors, psychologists, counsellors. Many of us are still passionate and still trying to make change.

My grandmother's death and other deaths when I was a teenager really sparked a curiosity that has never left me. I'm constantly curious about death and dying and loss and grief and what it means as for us as individuals

and as a society.

What's your hope for your role as clinical manager for NALAG?

I hope to be able to help strengthen and grow the work of NALAG, and I'd like to see us grow our volunteer base as well as strengthen the way we do our support work. I'd like to also look at how we extend our support to the more general community. I have a strong background in public health and promotion. One of the key themes of that work translates into the way we practice grief support by looking at the fact that 55 per cent of the population will be find with the help and support they get from their friends and family through their grieving process; 35 per cent of the population needs a bit of a "leg up" – a little support from a volunteer, for instance, or some kind of informal support from a service of some sort – and only about 10 per cent of the population needs some clinical support from someone like me, a clinical psychologist. So NALAG's brief lies within that 35 per cent and we do that really well. Because my position is funded by the Ministry of Health, my job is to understand how we evaluate that support and how we look at that in the longer term. That's something that's not been really done very well in Australia – that evaluation of and research into practice and outcomes. We know a lot about the 10 per cent, but we don't know that much about the group in the middle – that 35 per cent – and we don't know a lot about how you match what people say they need with what people get. That's something I think we can do well here.

"I'm constantly curious about death and dying and loss and grief and what it means as for us as individuals and as a society."

How have you seen the discussion about death and dying, and loss and grief, grow or change over the years of your experience working in the sector?

In some ways it hasn't, in other ways it has. For instance, we're still saying that death is a "taboo" subject, but it's not. Not really. Some of our messaging around death and dying hasn't quite caught up with the evidence. Our messaging is still a bit 1980s – people are still saying that people don't want to talk about death and dying, but actually there is heaps of

evidence to show that people DO want to talk about it. There's not a lot of development around the language.

But at the same time, we've had this growing field of professional and paraprofessional practice really pushing us along – death "doulas" or death midwives, end-of-life educators out in the community. There's been a proliferation of organisations and initiatives, nationally and worldwide, looking at the way we approach death and dying. Ten years ago, when we were just starting on the social media journey, people were afraid to get into it – there wasn't much around and people weren't having those discussions – but now you can go to YouTube and access all manner of discussion. It's certainly a place where you can educate yourself around all aspects of death and dying.

What we call death literacy in the community seems to be growing and more people are connected to their rights. We are moving beyond advocacy – which health professionals do really well – and more into activism. There are a lot of activists in the space now who are saying enough is enough; you can't do things like tell people they have to go to a funeral director, that's not okay and we have to stop that. If we want people to have choices at the end of their life, then they need to know the full range of options. This means that funeral directors, health services, hospitals, policy makers – they are all going to have to get out of their comfort zones now because people are going to come to them educated on their rights and options. That has to be a good thing for people, particularly vulnerable people who don't know what their choices are.

The industry – health professionals, death workers and anyone working in the death space – need to change with the times, because people are going to turn up on their doorstep armed with education and knowing their rights.

That's a big change that's happened, and one of the biggest challenges for those change-makers is that they're trying to do this work and the community really values it, but when they come up against "the system" it's really hard to facilitate what the person who is dying, or their family, really wants.

That's the activism that's happening now. Thirty years ago, we were all about dying and advance care planning and that's helped, but advance care planning isn't necessarily making

the changes we need in the system. The system needs to keep pace with the growing mood for choice and options that's come out of the advance-care movement.

For instance, hospital policies need to change to allow, within the law, for the wishes of individuals and their family. For example, it is a family's legal right to take their loved one's body home (NSW law allows for a body to be kept at home for five days) but most hospital policies don't allow for that – that needs to change. Policies need to facilitate that legal right because the logistics of taking a body home need to be in place.

We need to educate services as well. Health professionals, death-workers, places like hospitals, nursing homes, care facilities and services like NALAG – we all need to be death literate as well. We need to know the law. Because, for instance, if someone deeply wants to take their loved one home and can't even though it's their legal right, that's going to significantly affect their grieving process. We need to be across not only the law, but the ways in which we can facilitate those wishes.

We can be so paternalistic in our approach to what we THINK people need in their grieving process – sort of, "we know best".

So one of the things that NALAG needs to do, as a leader in this space, is to help that education and promote death literacy?

Yes, absolutely. Death literacy should no doubt be one of our core objectives. We know that death literacy is four things: skills, knowledge, taking action and learning from experience. Health professionals have such specialist roles and in palliative care, for instance, they're amazing at symptom management and the role they have, but that doesn't necessarily mean they're death literate. The general community is starting to gain that knowledge and for those of us in the system, that can be a bit of a challenge because those people are going to funeral directors and saying, "I don't want that, I want this..." and they know their legal rights because any good death education these days teaches you about that.

What do you see as the most urgent need in the palliative care space in Australia?

I come from a social model of health, so for me the burning issue goes back to the grass roots and how we are supporting each other as



About Dr Kerrie Noonan

A little about Dr Kerrie Noonan:

Kerrie is a clinical psychologist, and is the newly appointed clinical manager at NALAG, based in Dubbo at the Centre for Loss and Grief. She has been a pioneer and passionate advocate for creating a more death-literate society that can build community capacity for compassionate approaches to death dying and bereavement. Prior to joining the NALAG team, Kerrie worked as a clinical psychologist in palliative care and a social researcher with the Caring at End of Life Research Group at Western Sydney University. She was the founding executive director of The GroundSwell Project and national initiatives such as Dying to Know Day, FilmLife Project and ComComHub. She is active in the Compassionate Communities movement internationally. Kerrie was awarded her PhD in 2018 by Western Sydney University for her study titled *Renegade Stories: A study of death-workers using social approaches to dying, death and loss in Australia*. Her clinical experience has involved palliative care, health psychology, loss and grief, pain management, program development and evaluation research. She has a long history supporting and mentoring volunteers in the loss and grief area.

a community. I'm deeply interested in what we call the 95 per cent rule which says that if you have a chronic or terminal illness, in 95 per cent of cases you're with your family, your friends, yourself – you're in a social environment. Even if you're in a hospital,

you're with other people. It's only five per cent of the time that you're in a professional zone with a health professional. Now that five per cent is important in terms of symptom management and palliative care professionals are fantastic at that symptom management.

I'm interested in that 95 per cent. That's where the real social impact is. So if we were more death and grief literate, more able to support each other and more able to connect with our neighbours and family and friends, then there's greater interconnection with loss and grief and death and dying with the social environment.

One of the greatest challenges is that we have these silo experiences – there's treatment, then there's palliative care, then there's the funeral director and then to a bereavement counsellor. The only constant is our family, friends, community, schools, workplaces.

So how do we develop that common thread in such a way that we're better able to support each other as a community? That's where we'll make social impact. That's where we'll make a difference to everyone in their loss and grief. That's what will stop the 35 per cent from flipping into the 10 per cent.

Is that what makes NALAG's newly established palliative care volunteer program so important?

Absolutely, and I'd like to see it grow but also to look at social models of support. We need to look further than just the one-on-one support to how our communities support each other.

How can we better inform policy makers? That's a really good question. I think NALAG is in a unique position to do more research about the work that we do, and evaluation of the work we do. At the moment we have great and positive anecdotal evidence of the effectiveness of our service – people like coming here and tell us we've been enormously helpful and that's great. However, NALAG could be a leader in looking at the impact we deliver for communities and therefore inform policy, because that's not a well-researched or understood area.

Bereavement services are massively underdone, particularly in regional areas. We have a really unique model with NALAG and it offers enormous benefit to communities, but we're not quite showing how we deliver that

benefit. That could really influence policy, particularly in regional areas.

When you look at the statistics around the number of people who are projected to die, how they're going to die and what they're going to die from, we know that we are absolutely going to have a massive number of people who are going to need good symptom control and good care at the end of their lives.

The next 20 years is going to be massive for end-of-life care, there's no way around it. We can build cancer centres until the cows come home – and that's great and there's a huge need – but not everyone who is treated for cancer is going to survive. We also have a huge need for our ageing population who need care as they approach the end of their life. That's not just medical care, but social care to help deal with the grief, the isolation, the social interconnectedness – that's where the big social impact can be made and that's where no-one puts any money.

If you had a magic wand, what would be first on your list in terms of death literacy? One thing that would make a massive difference would be to see the development of palliative care policies like we have for ageing.

Take for example, councils. They often have a policy around ageing – how we're going to manage and ageing population and so forth. They'll have an ageing policy, a wellbeing policy, a community development policy but never do they have a palliative care policy. They never talk about death. How can you talk about wellbeing and resilience if you're not also going to talk about one of the most important life events: death, and loss and grief and facing your own end-of-life?

If I were to go really big picture and massive magic wand, imagine if every council in Australia talked about loss, death and dying as part of their wellbeing policy. Imagine if every workplace had to think about how they care for employees who are grieving, or are caring for someone who is dying.

How can we become a more compassionate and caring society if we're not addressing this issue? Something has to give.

As told to Jen Cowley.

DYING TO KNOW

What is palliative care all about and how can it help?



It's a term with which most of us are aware, but what exactly is palliative care? How can it help and what are some of the things we need to know as both consumers and carers?

Palliative care refers to the kind of support that helps people to spend their lives in as comfortable, dignified and pain-free a way as possible when they are living with a terminal or life-limiting terminal illness or condition.

According to the nation's peak body, Palliative Care Australia, palliative care is person and family-centred care that is extended to a person who is living with an active, progressive, advanced disease, has little or no prospect of cure and who is expected to die. The overall goal of this kind of care is to optimise the quality of life for the person who is dying.

Palliative care may begin at any time following a diagnosis, but end-of-life care refers to the last few weeks of life in which a person with a

life-limiting illness is rapidly approaching death – a time at which the needs of patients and their carers is more acute.

Because it is a family-centred model, family and carers can also be given practical and emotional support, and the end-of-life phase might also extend to bereavement care for loved ones following the patient's death.

There are all kinds of services offered when a person is receiving palliative care for symptoms ranging from the physical through to social, emotional or spiritual. Some of these include:

- Relief of pain and other symptoms associated with pain;
- Resources such as equipment needed to assist with caring for the person at home;
- Help for families to come together to talk about sensitive issues;
- Links to other services such as home help and financial support;
- Support for people to meet cultural

obligations;

- Support for emotional, social and spiritual concerns;
- Counselling and grief support;
- Referrals to respite care services.

Who can access palliative care?

Anyone, of any age, who has been diagnosed with a serious and incurable illness or condition may be able to access palliative care. When we think of terminal illness, we often think firstly of cancer, but there are many serious illnesses that may be life-limiting, terminal or incurable. For instance, in this edition of *Changes*, we speak with the chair of the International Movement Disorder Societies Task Force on Palliative Care, Victor McConvey, who discusses the value of access to palliative care services for people who are living with serious movement disorders like Parkinson's Disease.

As Palliative Care Australia says, for some people services can be beneficial right from the time of initial diagnosis, and may also sit alongside other treatments given by health care professionals.

The team that delivers palliative care services can be diverse, including general practitioners, aged care workers, medical specialists and other health care providers. But family and other carers, as well as volunteers, can also have an important role to play. All these people can work together, supported by specialist palliative care services should the patient's symptoms become difficult to manage.

Where does palliative care take place?

In short, palliative care can be provided wherever the person and their family or carers choose, wherever that is possible. This could be at home, in hospital, in a hospice or in a residential aged care facility. Many people say their preference is to die at home and a palliative care team can assist with whatever is needed to make this choice possible, but it depends on a number of factors including the nature of the illness and the level of care the person needs; how much support the person's family and community is able to give and whether there is someone at home who can provide physical care and support for the person.

Source: Palliative Care Australia - <https://palliativecare.org.au/what-is-palliative-care>

Caring and sharing: How to help someone who is dying

It's never easy when someone you care about is dying. Palliative care professionals and volunteers understand this and will help guide you and support you as you care for your family member, your friend, your loved one. Here are some discussion points, with thanks to the NSW Cancer Council, that you might find helpful if you are a carer or are supporting someone who is nearing the end of their life:

Time to say goodbye

The diagnosis of a life-limiting illness can offer you, and your loved one, the chance and time to "say goodbye". You can encourage the person who is dying to share their feelings, and you can in return share your own. This can be a prompt for important conversations that can be precious and memorable. Sharing your feelings also opens up an opportunity for you to tell the person who is dying what they mean to you and how you might choose to remember them. In turn, the person who is dying may want to do something as a lasting legacy and this is something you can help with, such as documenting their life or writing letters to family and friends. They might want to visit a special place that has meaning to them, or they may ask to contact someone special. These are things that can all be part of the process of saying goodbye and they are things you can help with.

What do I say when I don't know what to say?

It can be very difficult to know what to say to a person who is dying and it's quite understandable to be at a loss as to the right words. It's also quite understandable to be worried about saying the wrong thing, or finding the right thing to say to express your feelings in such a difficult situation. The worst thing you can say is nothing.

In her book, *The Etiquette of Illness* (2004) Sue Halpern suggests asking, "Do you want to talk about how you're feeling?" rather than "How are you feeling?" This approach is less intrusive and demanding and also allows the person to

choose whether or not to respond.

Tips for Caring:

Listen to what the person dying tells you. They may want to talk about dying, their fears or plans. Try not to prompt an answer that confirms what you think or your hope that things could be better. If you think they'd find it easier to talk to a spiritual care practitioner, offer to put them in touch with one.

- Try to treat someone who is dying as normally as possible, and chat about what's happening in your life. This makes it clear that they're still a part of your life.
- Avoid talking with an overly optimistic attitude, for example, by saying "You'll be up in no time." Such comments block the possibility of discussing how they're really feeling – their anger, fears, faith and so on.
- Apologise if you think you've said the wrong thing.
- Let them know if you feel uncomfortable. They might be feeling uncomfortable too. It's okay to say you don't know what to say.
- Ask questions. Depending on how comfortable you feel asking direct questions and on their willingness to talk, you might ask, "Are you frightened of dying?" or you might prefer a softer approach: "I wonder whether there's something you want to talk about?"
- Just be there. You don't need to talk all the time. Sometimes it's the companionship that is most appreciated – sit together and watch television or read.
- Encourage them to talk about their life, if they're able to and interested. Talking about memories can help affirm that their life mattered and that they'll be remembered.
- Accept that you or the person dying may cry or express anger. These are natural responses to a distressing situation.
- Even if they've shown no religious interest in the past, that could change as death approaches. You could offer to pray together, but respect their wishes if this is not something they want.

How else can I help?

There are many things family and friends can do to help support someone at the end of life, including:

- Prepare meals – Preparing meals for someone who is sick can become complicated as their needs and illness change. Try cooking simple, small meals. You may have to mash food so it's easier to swallow – the palliative care team will have a dietitian who can advise you on what is needed. As the disease progresses, the person may lose their appetite and not be able to eat or drink. At this time, it's important not to force eating or drinking. If the person cannot drink, chips of ice can help to moisten the mouth.
- Manage medicines – If you need to give medicines and feel overwhelmed, ask your doctor, pharmacist or nurses for suggestions. For tablets and capsules, a blister pack can set out all the doses that need to be taken throughout the week.
- Help with bathing and washing – If the person you are caring for can't move around easily, you may have to sponge bathe them or wash their hair over a basin.
- Help with getting in and out of bed – It's common for a dying person to spend more time in bed. You may need to help them get in and out of bed, roll them over regularly so they don't get bedsores, or lift them to change the sheets. You can use equipment to help with lifting. Many people create space in the living room for the bed, particularly if bedrooms are located upstairs. The palliative care team can help you provide this care and arrange equipment such as a hospital bed.
- Assist with toileting – You may have to help the person get on and off the toilet or commode, help them use urine bottles or bed pans if they can't get out of bed, and sometimes help them to wipe themselves. Lifting someone is hard work and you may need help with this, either from another person or mobility aids or equipment. An occupational therapist can help you choose suitable equipment.

- Sort out the paperwork – For many people who are dying, getting their affairs in order can help them feel like they've given closure to their life. You can help gather important documents, discuss the person's choices for their future health care, and arrange legal advice if needed.
- Record social media details – People often have more of a social media presence than they realise. You can help the person work out which social media accounts they have and what they want to happen to these accounts after they die, and then help compile a list of passwords and instructions.
- Do odd jobs and run errands – Friends can offer to step in with walking the dog, mowing the lawn, picking up the kids or doing the shopping – anything that eases the workload of the main carer.

Source: <https://www.cancercouncil.com.au/cancer-information/advanced-cancer/end-of-life/for-carers/emotional-support/>



Photo Credit: Erin McGlynn



Photo Credit: Annette Furguson

Q&A

The Hon.
Bronnie Taylor,
NSW Minister for
Mental Health

From Palliative to Parliament

Before taking the leap first into the NSW State Parliament in 2015 and then into the portfolios of Mental Health, Regional Youth and Women, BRONNIE TAYLOR spent two decades as a registered nurse, specialising in cancer care and palliative care. As a part of that work, she became one of the first McGrath Foundation Breast Care nurses, and went on to become Director of Cancer Services in the Southern NSW Local Health District. She describes herself as an “accidental activist” who became involved with politics out of a frustration with “the system” and its implications for regional patients. Bronnie is the mum of two daughters and is part of a family farming operation at Nimmitabel in southern NSW, and took time out from a hectic parliamentary schedule to talk about her experience in the palliative care sector and how it helps inform her ministerial role.

What’s the greatest challenge you see facing the palliative care sector in this country at the moment?

I’ve been out of the palliative care and health system for some years now but I think one of the hardest things, the real challenge, for palliative care now is the continue of care and the constant juggle of when to bring palliative care into the mix.

Even just the name “palliative” has many obstacles in bringing it into play early. I did palliative care specifically with cancer patients,

so my title was “cancer nurse” rather than palliative care nurse. We changed the title of the position because things change over time with treatment and prognoses. When I first started in the profession, if you were diagnosed, for example, with metastatic bowel disease and liver progression, you knew you had a fairly time-limited life-span. Five years later though, the prognosis was much better for that condition – you could go on for a decade or more, thanks to developments in treatment.

So I think it is really about incorporating the clinical skills of palliative care within jobs that exist as well so that you don’t have this separate entity – it all becomes part of the whole strategy of caring for someone as they progress towards the end of their life.

Do you see a contrast between palliative care services available in the city and in regional areas?

It’s really beautiful to be around people when families are brought together through a time that is extremely sad and very difficult but that really is part of life. It’s a privilege to be able to share in that time and to be able to help that patient and their family. In regional and rural communities there is a really strong sense of valuing people and valuing their contributions within their community and in various groups, so at the end of a person’s life, people really come together and look after each other.

When my husband’s mother died back when he



was 20, I think they were eating frozen food for two years afterwards! It's amazing and it's lovely that, in the country, people just arrive to help – they don't intrude, they don't impose, they just offer really sensible and practical solutions.

I grew up in the city and when my father died, some of our neighbours didn't even know he was ill, and some didn't realise he'd died until a couple of months after. That's the stagnant difference.

I think we have so much to learn from small communities about end of life care.

How has your experience in nursing in general and palliative care in particular helped to inform your practice as a parliamentarian and now, as Minister for Mental Health?

I never realised how much of my nursing experience I used in my everyday life until I left the profession! One of the fantastic things that nurses do is problem solving, and I think my experience as a nurse and in palliative care has given me some great problem-solving skills. I'm faced with a problem and I find a solution. That's what nurses do every day for their patients.

The other thing that working in end-of-life care teaches you is to be a keen and perceptive observer. You're looking for those subtle clinical signs so that you know when the end is getting closer and that enables you to keep the family informed. You can help prepare them, as much as that's possible, and you can adjust your care plan accordingly.

That's a skill – the ability to observe – is one I now use a lot in parliament. I think that gives me an edge over some of my colleagues and I'm very, very grateful for my nursing training.

I say to people who are embarking on doing nursing or specialising in the fields I went into, it's a wonderful profession but it's a profession where the skill-set you develop can transcend the job and go with you into any career or profession.

What is the most important element of palliative care and what do people need most, in your opinion, when they're facing the end of their life?

I think people need time. They need your time. When you're a palliative care nurse, and certainly where I worked, I was given the great privilege of being able to give my patients my time. I could sit with them; I could sit with their families. I never felt as though I needed to rush from one patient or room to the next. Even though at times our workloads were excessive, we had an incredible community health team and they would pitch in and help.

Now, so much is done in a "task-oriented" way and I think that one of the greatest attributes of a palliative care nurse is that they're able to look at the patient as a whole person. Physiologically there's so much going on, so many physiological symptoms, that you have to be across it all. That's one of the unusual things about caring for someone who is dying – that holistic view.

But if I had to name one thing, it's time. And a respect for people – all people. That's a skill you must have to be an effective palliative care worker.

NALAG has for some time now been part of a wider push to change the language around death and dying and to discourage the use of euphemisms. Do you think there's a place for more open and direct conversation?

I do. And there has to be great co-ordination with the whole treatment team – between the doctors, the physios, the OTs (Occupational Therapists), the pharmacists – because we all know that the patient will go and have a consultation with one specialist who tells them there's a three per cent chance this treatment might work if they choose to take it, and often the patient and the family will hear the "97 per cent" rather than the three per cent. So yes, we

"I would like to see that lived experience model used to encourage people to volunteer in the palliative care space, but we really need to make sure there are the structures in place to support those volunteers. That's why it's so important to have organisations like NALAG."

need to have honest conversations but what also needs to happen is other members of the treatment team need to be on the same page.

I was always conscious, and able fortunately, to work very closely with the treatment teams so then I could reiterate and reinforce that information the patient and family had heard from the specialist because often they don't or can't hear past that first one or two sentences.

Often, we can be so afraid of saying the facts out loud if we think they're going to be too daunting or if they're very sad, but in my own personal practice, people would surprise me every time. They know what you're going to say.

What would your advice be to families going through palliative care?

Plug yourself in to your palliative care team. Don't think that the end is just around the corner just because you've been referred to palliative care because that's not necessarily the case.

We need to have palliative care introduced from the very beginning, so that people know that it's available and know that it's there.

The skillset of palliative care professionals is so fantastic that if you can have that early intervention, you can have a much higher quality of life.

NALAG now has a palliative care volunteer program that's in its early stages. What role do you see for programs like this?

The volunteer element – those who are giving their time to assist with palliative care – is absolutely fundamental. I love groups like NALAG that can provide not only the training but the support for volunteers to do the job they do – that's paramount in any palliative care practice.

Being from a regional area, you're familiar with the challenges of life in rural communities, particularly during such difficult times as this current drought – what are you seeing in the mental health and palliative care spaces in regional NSW at the moment?

With palliative care, we've had some great improvements and the injection of funds a couple of years ago (\$100 million for palliative care services in NSW in the 2017/18 budget)

made a big difference. I really take my hat off to organisations like NALAG and Palliative Care NSW – they're really flying the flag well, and making people aware of the necessity of talking about palliative care and its value to the community.

I like seeing palliative care being talked about and considered so widely, and that we're looking to place those specialists where we need them. With regard to mental health, there are enormous challenges with this drought and the impact it's having on people's wellbeing. We're also seeing the ravages of the bushfires across the state, and that's something I'm working on specifically at the moment.

But we've definitely seen an increase in discussion of and diagnoses of mental health conditions across Australia – but I actually think there's a positive story to tell there because it means we are breaking down some of the stigma that has existed for generations, so people are putting their hands up for help.

That excites me.

One thing the mental health sector does so well is that they use people with lived experience (to assist) and I think we could use that model more widely across the whole health system.

"Often, we can be so afraid of saying the facts out loud if we think they're going to be too daunting or if they're very sad, but in my own personal practice, people would surprise me every time. They know what you're going to say."

I would also really like to see that lived experience model used to encourage people to volunteer in the palliative care space, but in saying that, we really need to make sure there are the structures in place to support those volunteers. That's really important – and that's why it's so important to have organisations like NALAG.

I'd like to see everyone have good access to palliative care services so that if, for instance, they choose to spend their last time or days at home, they can and that the continuity of contact with their clinician is there to allow those choices.

Are you enjoying your role as a parliamentarian generally and as Minister for Mental Health specifically?

(Laughs) You know, it's funny – when you tell people you're a politician, they're aghast, but when you tell them you're a nurse they think you're fabulous. So that's been a huge change for me! (The role) is really challenging – I work really, really hard. People think we (politicians) don't but I genuinely work really hard. It's fantastic to have a portfolio in health – I love being back and involved in the health space. It's the reason I came into politics – to make changes in the health sphere.

One of the real challenges for me is that I have to be away from home so much. When you're a member of The Nationals and you're a rural/regional member, it's one of the things you have to juggle. I'm five and a half hours away from my home at Nimmitabel and I'm sitting here in Macquarie Street in Sydney talking to you – it's been a really long week, and I really just want to be home with my family and my husband whom I adore... and that's really challenging. It's the same for any member of parliament who doesn't live in the city.

But apart from that, I just see this job as an incredible opportunity. None of us is here for a long time but I'm going to make jolly sure that I work as hard as I can to make a difference for the clinicians out there – I owe them that, that's my responsibility.

You're Minister for Mental Health among other things. How do you take care of your own mental health?

I love being home when I can "un-plug" back on the farm – that's essential for me. I don't love exercise, but I make myself do it! I have a fabulous trainer in Cooma and I try to get to her whenever I can, but I find that exercise really helps my mental wellbeing.

I have a very wonderful set of friends who sit outside politics and have no interest in it, so for me, spending time with them is like soul food. That, and just getting back to basics and doing things in my own community with the people I love is how I look after my own mental health.

As told to Jen Cowley



Photo Credit: Annette Ferguson

A Stranger in the House

A carer's tale



Where does “palliative care” begin? When is it that we begin to provide those elements of care and comfort central to what is considered the “palliative status”? JENNY PERINO, Co-ordinator of NALAG’s Hunter Region branch examines this question not only from within the context of professional support to validate the experience of other carers, but from a deeply personal perspective.

My own journey began prior to an actual diagnosis when I considered that it must be me “losing it” when people would placate me and tell me “we all forget things”. They would dismiss those elements of odd behaviour my husband was demonstrating. Interestingly,

when those same people were no longer comfortable with these odd behaviours or absences of mind they’d so easily dismissed before, they disappeared from our lives, leaving a social isolation that is tangible.

Considering a formal context, does palliation begin at the point of diagnosis when carers are already familiar with the daily struggle? The odd behaviours are like a stranger visiting. The only change was that now the stranger had a name...Lewy Body Disease (LBD). This stranger was introduced to us with a direction and a timeline and was to accompany us home that day to become part of our lives.

Perhaps palliative care begins on that same day when the specialist clearly states that within three years your husband will be in full-time residential care? Is it that Saturday three years

later when he goes off to bowls and the call comes to say he is on his way to emergency in the ambulance? Or does it come a few days later when the doctors tell me they will not be able to allow my husband to come home and that he'll go straight to the nursing home?

Meet anticipatory grief: it's the grief that begins long before the actual death of a loved one. It's the loss that starts for carers as they absorb the increasing needs of that significant other, sometimes even before a formal diagnosis is apparent.

There is a flux between acceptance and denial not only for the one with a restricted prognosis but also for the carer. Is it wishful thinking? Hope beyond hope? I'm not sure.

"My husband has been more than four years in a care facility, but I now I wonder perhaps if the palliative care begins on that final admission to emergency...with the words "there's nothing more we can do".

Certainly, when that movement to a nursing home came, I questioned myself: Who am I now? I'm not really a carer anymore. I'm not a wife but neither am I a widow. I don't know where I fit anymore. It took some time for me to resolve that identity dilemma, but a very real dilemma it was for me. When some family members evacuate the sinking ship, the aloneness and identity crisis compound the grief and there is a sense of going it alone.

Lewy Body Disease is unfamiliar to most people and even to many in medical and care circles. However, it is the most insidious and cruel of the dementia spectrum conditions, encompassing elements of Parkinson's (movement disorder) and Alzheimer's (memory impairment) with the added elements of visual disturbance, hallucinations, paranoia, sleep disorder and cognitive impairment.

There are good days and bad days. An unpredictable condition, LBD teaches you the true meaning of the saying, "expect the unexpected".

As a carer, the elements of palliation – to

provide comfort and care – seem ongoing and the struggle continues moment to moment in what seems like endless elements of the carer role, including multiple trips to emergency departments for physical injuries due to falls, blackouts, risky behaviours and/or hallucinations.

My husband has been more than four years in a care facility, but I now I wonder perhaps if the palliative care begins on that final admission to emergency when he is sent back to the care facility with the words "there's nothing more we can do". The nursing home is now documenting a formal end-of-life plan and I ask, "What are we talking time-wise?" The managers look at me intently during a very pregnant silence while they assess my potential reactions.

Finally, words break the silence: "We're not talking months...perhaps weeks". What I suspected has been verbalised and while I'm not sure I wanted to hear it, I guess I needed to hear it so that I can keep that touch with reality. Now, more than ever, I need to advocate for what my husband wants and what he needs.

So I busy myself with the practicalities. I let the family know, which is not something that can be done in a text message. It needs to be a personal call to break this news and manage their emotional responses. They will all come to visit regardless of the fact that most of the time he doesn't know who they are...or who I am.

On a good day there is some level of recognition. There's a familiarity even though he doesn't know my name or where I fit in his life. His children have to be introduced again each time as all becomes lost along the journey. The empty eyes that tell me he has already left me. Where has his spirit gone?

The practicalities taken care of, I return home to my own thoughts and the fatigue that takes me over. Morning breaks... and so do I.

I hear John Farnham's song "Burn for you" and a silent tear betrays me. A feeling rises from my lower rib cage, taking me over, as if my body is squeezing out a wet sponge saturated and dripping with grief.

"What am I gonna do?", says the song's lyrics. I ponder, and role-play in my mind how that will work when the time comes but I'm still faced with the now. The moments are pregnant with loss. My grief is kept deeply private with a changing environment that makes me dizzy.

"It is so hard to explain to you," Farnham sings. Having experienced and lived with the nuances of this disease, it's like an intimate relationship with a stranger that moved in.

'Please understand what I do....' But no-one does understand, not even those closest to us.

Internally I am alone in the most overwhelming sort of way. Even when I am with my husband, he is so distant. I can hold his hand but can't touch him. I look into his eyes but he is not there. Those empty eyes are as if his soul has left him and his spirit is on a different journey.

The journey has been one of multiple and repeated loss. The grief has been present for both my loved one and me each day as this stranger has taken over our lives. In the earlier days we would discuss that this wasn't the way we planned the latter years of our lives. The vision was shattered when that stranger moved in.

This condition, LBD, has stolen the strong body that always worked so hard and was capable of almost any physical task. It has stolen his speech; his ability to communicate to those around him on even the most basic level. The garbled sounds defy interpretation so that he can no longer express his needs or tell me of his pain or ask for help.

Regardless, I must press on. I hold out for the good days when there is recognition and knowing; a day when the eyes are not empty but look at me and actually see me and there is a glimmer of smile and he is present with me once more if only for a moment. I need to be there when that moment comes. My phone stays on all night. I carry it with me and prepare myself each time the nursing home is identified on the ring. I need to fight harder now that he can no longer fight for himself.

In those increasingly rare moments when he knows me, I'm on a high for days but all the

while wondering what will come next, knowing this too will change. So I tell myself not to hope.

How does one prepare for loss when grief has already begun with loss that is ongoing and complex? LBD was the stranger that came to stay, robbed us blind, took a loving husband and left behind another stranger in an empty body, akin to the living dead.

Friends disappear – no one seems comfortable with an individual with dementia. All those golfing buddies who promised to visit have faded. Family members who were never very involved with our lives run hot and cold, perhaps there for the drama when an opportunity presents but absent the rest of the time.

However, there are others that have been so supportive of me as a carer; aware of the constancy of my role. They are the ones who keep me going and to whom I will always be eternally grateful.

Meanwhile the unpredictability of LBD continues. That prognosis of weeks has expired and we continue to face each day as it comes.

Palliative Care and Movement Disorders

Time for a rethink



When it comes to palliative care, we tend to think in terms of terminal diseases like cancer as the conditions that trigger end-of-life support. But as the chair of the International Movement Disorder Societies Task Force on Palliative Care, VICTOR MCCONVEY says we need to think differently about the need for this specialised care and support for those living with conditions such as Parkinson's Disease.

There are an estimated 87,000 Australians living with Parkinson's Disease and possibly more than 3000 with the much rarer Atypical Parkinson's conditions of Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico Basal Syndrome (CBS).

So, when does palliative care start for a person with one of these conditions? Considering none of the available treatments slow or stop the conditions and can only provide symptomatic relief, some would suggest palliative care should start on diagnosis. Referring someone on the point of diagnosis is probably not palatable for the individual, and palliative care services providing support for decades under current funding models is not feasible.

There is limited evidence suggesting when our thoughts should turn toward taking a more palliative approach in Parkinson's and Atypical Parkinson's. Frequent falls, increasing swallowing difficulties, cognitive change and carer strain may provide some red flags as can the emergence of neuro-psychiatric symptoms.

People living with these conditions will experience these symptoms individually and at

different points of progression, making prognostication challenging. To compound this situation, there is no clear pathway for a person with a progressive neurological condition to be referred to a palliative care service and acceptance of the referral will depend on available resources in that region, subjecting people to a postcode lottery.

For many people palliative care will need to be initiated within the aged care sector. There are well documented challenges in the aged care sector for people living with movement disorders and the health professionals charged with delivering care. Limited understanding of the conditions and treatment needs can make delivering appropriate care difficult. The individual's complex presentation and unpredictable motor and non-motor symptoms may also make it very difficult to identify when the person living with Parkinson's or an Atypical Parkinson's condition is nearing the point at which palliative care is needed.

"The absence of services or formalised care pathways for people living with these conditions which support a timely transition to palliative care can be identified as a gap globally."

A frequently unacknowledged challenge comes with the cumulative losses and feelings of grief people experience over years as the symptoms of the condition slowly impair function and impact on quality of life of the person with the condition and their family. These losses can be as simple as illness impacting on intimacy and the need to accommodate illness into the most personal part of life, amplified by an absence of available help. These cumulative losses may not prepare the person and their family for end of life or decisions surrounding palliative care but may result in feelings of relief and guilt when death occurs.

The absence of services or formalised care pathways for people living with these conditions which support a timely transition to palliative care can be identified as a gap globally. In a soon-to-be-published review by the International Movement Disorder Societies Palliative Care Taskforce, pockets of excellence in delivery of palliative care for people with



About Victor McConvey

A little about Victor McConvey:

Victor McConvey has been a Nurse for 30 years and has worked in the area of neurology for the past 20 years. He has worked in clinical management and service development positions in both Australia and the United Kingdom, including establishing the Parkinson's Nurse Specialist position in Leeds (UK). Victor is currently employed as the Clinical Nurse Consultant and Manager of the state-wide Health information and education service at Parkinson's Victoria. In this role he works across the state educating health care professionals about Parkinson's and working with consumers on managing symptoms and improving self-management. Victor is currently the chair of the International Movement Disorder Societies Taskforce on Palliative Care and leads the Health Care Professional section of the society. Victor is also a presenter, chair and sits on the clinical advisory team for the World Parkinson's Congress, June 2019 Kyoto.

movement disorders are identified. However for the majority there is an absence of services. Encouragingly, the task force has identified a willingness for physicians to increase skills in palliative care and the best response should be multidisciplinary.

Within Australia, the palliative care sector can be identified as having a willingness to provide

support for people with complex neurological disease. In Victoria, palliative care services receive additional funding when they are supporting a client with Motor Neurone Disease (MND). The additional payment reflects the complex care and multidiscipline support needs of people living with MND and raises the question as to whether similar support could be extended to support people with Parkinson's and Atypical Parkinson's who, in the advanced stages, have similar needs.

The numbers of people living with Parkinson's and Atypical Parkinson's are growing with a looming Parkinson's pandemic predicted. People living with these conditions are also wanting more control and the ability to participate in decision making, demonstrating this by developing Advance Care Plans identifying care, which is acceptable, and for some seeing voluntary assisted dying as an option where available.

We do need to think differently about palliative care for complex neurological conditions such as Parkinson's if we are to meet the future challenges and support people to live well and to die well. Models such as neuro-palliative rehabilitation pathways (according to the Royal College of Physicians concise treatment guidelines No.10) and significant research projects such as the European wide PD PAL project are developing an evidence base and providing the framework to enable people living with Parkinson's and Atypical Parkinson's to receive the palliative care they need and deserve.

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Tell Someone who Cares

The Vital Role of Palliative Care Volunteers

LYN SYKES has an extensive background in counselling, most notably in the niche field of family succession planning. Now, the seasoned advocate is on a self-described “sharp learning curve” after recently following her instincts, and an identified need, into the vital area of palliative care through a newly established NALAG volunteer program.

Two things awakened my interest in palliative care.

Firstly, I was asked to speak at a couple of palliative care conference in my capacity as a succession planning professional. At one of those conferences I heard a woman speak about her experiences as a volunteer with palliative care at one of the Sydney hospitals – I was really taken by what she said.

I thought that in a community the size of Dubbo, surely there was a need for palliative care volunteer services. I quietly looked for opportunities but there didn't really seem to be any forthcoming.

The second thing was that a neighbour of mine was dying and fell really ill on Christmas Eve and what I learned from that was not to die on a public holiday. It really reinforced my belief that if employed people (in the health professions) are not available, there really needs to be someone around to support and advocate for people who are dying.

Earlier this year, a friend said she'd been approached to join a palliative care volunteer team that had been operating in some of the small communities around the region but hadn't come to pass in Dubbo.

“In a volunteer role you need to have a reasonable amount of empathy; you need good listening skills; you need to not be judgemental.”

So there were four of us that undertook training to start to provide that volunteer service in Dubbo.

One of the requirements for setting up such a service is for a community organisation to be involved to offer support for the volunteer program and, as we've seen so often with NALAG, it put up its hand to fulfil that role in Dubbo and that's a natural fit. There's no funding attached to that, which seems unfair to me. The volunteers don't need funding as such, but the administration of the program and support for the volunteers does.

I'm on a pretty steep learning curve but as far as I can see, the essence of good palliative care support is providing whatever the client needs. Whatever that person who has put up their hand for support says they want, being able to assist with that is the essential ingredient. It needs to be patient/client driven.

“One of the things we find most important as palliative care volunteers is to be there for people to talk to, but specifically for them to talk to about dying. To talk about their fears and what they'd like to have happen; to talk about their fears about what happens after they've died.”

It's early days but so far, there are a few different things I've been able to do for clients. One of the clients I visited was very close to death – he wasn't aware of that at the time, although his family was. They took the opportunity to tell him more accurately about his prognosis while I was in the room – I think that would have been much more difficult for them had I not been

there, given I have some experience in facilitating difficult conversations in my succession planning practice.

He died very shortly after that and his family has since said what a great gift it was to have someone there to assist with that conversation – someone who had a few basic communications skills. So it was a privilege to be able to help them.

Another client who springs to mind is a lady who has a strong need to talk about dying, but her husband is unable to have those conversations with her, probably because of his own fears about what was going to happen. He was a fairly strong force and some people had found him intimidating, so it was helpful that someone who can probably be equally intimidating (me!) was coming to talk to his wife. And I could tell him that the reason I was coming was so that she would have the opportunity to talk about the things she needed to talk about that were too uncomfortable for them to discuss together. I told him he was welcome to stay if he wanted but if it was more comfortable for him I would understand if he chose not to stay while his wife and I had those conversations. And he chooses not to be there.

One of the things we find most important as palliative care volunteers is to be there for people to talk to, but specifically for them to talk to about dying. To talk about their fears and what they'd like to have happen; to talk about their fears about what happens after they've died.

What I hear from some of the other (volunteers) who visit people who are much younger, with younger children, need all sorts of different support and advocacy to assist with getting help through various agencies. Sometimes they just don't understand the processes of accessing support, so that advocacy is important.

I think it's really important to understand that when you're vulnerable, making decisions is not easy and having someone just to take you through that is helpful. So, for my client that I mentioned, just something as simple as talking with about going to the doctor is a help for her: What does she want from the doctor? What questions does she need to ask? What are the concerns she has? So even just to jot that down for her so she has that list when she goes to the doctor, or wherever, she feels prepared and is less likely to come away feeling quite so unsatisfied.

Another thing is providing advocacy with the home-care situation is another important need. There are people in Dubbo, and the same would be true elsewhere, who are dying and have no family support – that's a bit of a gap that as it develops, I think this program can help to fill.

What makes a good palliative volunteer? I'm not exactly sure and I'm still learning but probably first and foremost, you need to be someone who doesn't try to give advice. And you have to have a preparedness to not judge any situation or any decisions the client or the family might make. That's the same for anyone who works in a health-related profession, I suppose. But in a volunteer role you need to have a reasonable amount of empathy; you need good listening skills; you need to not be judgemental.

Strategies for keeping your own emotions in check vary, and I suppose those strategies will develop more with the help of NALAG as we progress with the volunteer support program. But the main thing is to have the clinical services manager in place, as NALAG does, to provide that support – to care for the carers.

I have always accessed clinical supervision in my own private practice and will continue to access those services as a volunteer.

I've had experience in my succession planning role with talking to families about "end of life" plans, but this volunteer role has reinforced what I already know: that talking about what your plans and wishes are is hugely important. All your family needs to be on the same page about what's going to happen to you and what you want, and the only way that will happen is if you sit down and talk with them about it.

One of the roles that I see as an easy and comfortable fit for me as part of this program is to talk to people about talking to their families because I've had a lot of experience with talking to families about talking about difficult things.

These are difficult conversations to have. No matter how old you are, your children don't usually want to talk to their parents about dying. At the very least, having a document that all of them can read is helpful because I know from my work that perceptions of what parents want can vary enormously amongst children, all of whom are sure they're right about what their parents wanted.

Most people are afraid to talk about dying because they're afraid of dying. I think that's understandable because it's the unknown. It would be great if someone could come back and tell us what happens and what it's like – that

would take the mystery out of it and maybe some of the fear. People are generally frightened of the unknown and death is the ultimate unknown, isn't it?



Life & Beyond

A little book with big impact

NALAG Hunter Branch volunteer LYNDsay LOWE talks about her book, *Life and Beyond: Instructions for My Family*, and how sharing your end-of-life wishes can help ease their pain when the time comes.

Life and Beyond: Instructions for My Family is a journal guide that sets out all the various things your family will need to go through when you die. It guides you through recording all the relevant information your family will need to know.

Not all parts of it are relevant for all people, but all people will find some parts relevant.

It covers everything to do with the kind of funeral you want; there's space for some personal history which can help with writing a eulogy; you can record your financial details (where to find accounts, deeds, records and so forth) and for the last edition, I even included some space for the recording of social media and internet passwords and that sort of thing.

It can help your family find documents – where your will is, who your solicitor is, if there's a power of attorney or guardianship arrangement, an advance care directive – all that sort of thing. It can be such a help to your family when the time comes, and if the worst should happen unexpectedly. The contents of the book are not chiselled in stone – you can change it or add to it.



Many years ago I picked up a brochure at a funeral home while I was helping a friend organise a funeral, and when I read the brochure it made me think about how much my family wouldn't know about my wishes or what to do if anything were to happen to me.

"I've met so many people who have said, "I wish I had this when my mum/dad/whoever was dying" because they've been thrust into this really emotional time without any guidance as to what their loved one wanted."

There were many points raised in the brochure that I realised could be expanded on to give my own family more guidance, so I began to

do a sort of journal in my spare time. That turned into the book and it's now in its fourth edition. With each edition I added more in response to things people had fed back to me about possible inclusions, and I think now I've just about managed to cover off on it all.

It's not actually a legal document as such, but there's a space at the end of the book for a signature so that if there were to be any disputes, it can actually serve in a court of law as a record and evidence of the writer's wishes.

Apart from being a legal record, there's also a significant emotional benefit in writing everything down regarding your end of life wishes. We know that when someone we really care about dies, we go through such a period of grief that it's hard to think about what our loved one wanted to happen.

I had that experience with my Mum – I couldn't think what kind of music she might have wanted at her funeral, and while that sounds like a small thing, that really brought me undone. If she'd written it down, it would have avoided that added heartache.

When you're going through that intense period of grief, you're not always thinking properly. So if you have your loved one's wishes and instructions all written down – their preferences for a funeral, their financial details, passwords, documents – that can make the process just that little bit less stressful.

Filling out the book can also be helpful to initiate a conversation about death and dying. I've done some group sessions with men and I find that men don't talk as much as women, who are more open to talking about death and dying. The book is a matter-of-fact way of broaching the subject and helping them to realise that end-of-life arrangements are something we all need to consider.

Australians tend not to be as open to talking about death. There is a lot happening out there in the space and conversations are beginning to happen, but there's a long way to go. I don't know why it's so hard to talk about, but it is really important in acknowledging that death is a part of life.

If someone has the book – and has filled it out, even in part – they can sit down with their family and say, okay, you might not want

to talk about it, but everything is in here – these are some of the things that I've decided and that you'll need to know when the time comes. It makes it so much easier.

I've met so many people who have said, "I wish I had this when my mum/dad/whoever was dying" because they've been thrust into this really emotional time without any guidance as to what their loved one wanted, or even where to find a will or things like that. They say it would have made such a difference to have had it all written down.

Copies of *Life and Beyond: Instructions for My Family* are available through the website: www.lifeandbeyond.com.au or contact Lyndsay directly on 0428 650294

A very personal experience

At the time of talking to Changes for this special palliative care edition regarding her book, *Life and Beyond*, Lyndsay was spending precious time at the bedside of a dear friend who was dying from cancer. She took time out from that vigil to speak with us about this very personal experience:

My experience as a volunteer with NALAG and with producing the book has helped me with being here for my friend Karen who is dying from cancer and is at the end of her life.

There have been some lovely moments and some laughs and some very funny moments, but there have also been some terrible times. It's made me even more supportive of assisted dying, or voluntary euthanasia because watching her go through the bad times has been so hard. It's really opened my eyes. Karen has said on a number of occasions that she just wants it all to be over. As things stand at the moment, there's no access to assisted dying for Karen, but we can at least support her through to the end because we've talked about it and we know that she's happy to go.

I have been with her for the past three weeks, and she's never been alone. It's been beautiful at times and it's a real privilege to share this time with her and do what I can. I just keep thinking, please let it be a kind, peaceful and pain-free death.

I'm not here with Karen as a health professional, but I'm still part of her palliative

care in that I'm here as part of a group of friends and family. She's had someone with her every step of the way. The hospital's palliative care team is amazing – they do such a wonderful job, and we've been here in a supportive and personal role to stay with Karen.

We have talked a lot about her dying and I've been able to draw on my experience with NALAG and with writing the book to talk not only to Karen but to her family.

If we're not prepared to talk about dying, then we're denying that person an opportunity to talk openly about their wishes or how they're feeling and to talk it through if they're facing their own death.

It's imperative that we talk about end-of-life care. If your friends and family know what your wishes are, it's so much easier for them to support you through that final stage of your life.

It's important that we continue to have the conversations about death and dying so that we can push for more support for palliative care services. There are some great organisations out there that are spearheading those conversations and there is more of a wide acknowledgement of the importance of end-of-life support and palliative care, but we need to keep going.

One of the things we've been doing through NALAG in the Hunter Region is having what we call "death cafes", where people get together to discuss services and it's working really well – the response has been great and we've had some very healthy and open discussions around death and dying.

Organisations like NALAG need to be proactive in this space so that government can be better informed and able to support palliative care as an important health service.

At the end of the day, it's about giving people choices and about making sure people have access and support for peaceful, kind and dignified death.

*** Karen died peacefully in hospital three days after this interview with Lyndsay, with friends and family supporting her to the end.*



Photo Credit: Annette Furguson



Photo Credit: Amy Gore



Photo Credit: Millah Bush

Through Indigenous Eyes

Exploring loss and grief through photography

Trudy Hanson OAM – CEO of NALAG



For many years, I have had a strong interest in and passion for supporting Aboriginal individuals and communities who are experiencing loss, grief and trauma. It is a privilege to visit, to sit and yarn, and over the years I have heard many Aboriginal people's stories of profound loss, grief and trauma. As renowned Aboriginal leader Charles Perkins once said: "We know we cannot live in the past, but the past lives in us".

HISTORICAL LOSSES INDIGENOUS PEOPLE HAVE EXPERIENCED

- Suppression of culture and cultural practices.
- Outlawed and forbidden use of tribal languages – indigenous people were widely forbidden to use their native language;
- Sickness introduced by Europeans (for example, measles)
- Land
- Lore (traditional)
- Traditional medicines and foods
- Many ceremonies, particularly grieving ceremonies

- Deaths and dying through massacres, many of which are now recorded and form part of the shame of Australia's history.

NALAG founder Professor Beverley Raphael believed that:

"Indigenous Australians experience similar emotions when in grief as any other race of people. The difference lies not in their human emotions but grew out of a range of losses since settlement in 1788. These losses contribute to their psychological, social and economic status."

Traditionally, Aboriginal people processed their grief predominantly through the use of their language, sacred ceremonies, and their strong connection to the land and their spiritual ancestors.

It can only be assumed that colonisers did not recognise the significance of Aboriginal culture, as not only have indigenous people suffered lack of recognition and loss of culture, they also

suffered the loss of their land and rituals which enable them to deal with these losses.

“The loss of land is significant to Aboriginal people and this has been apparent as NALAG has visited communities during the current drought.”

The loss of land is significant to Aboriginal people and this has been apparent as NALAG has visited communities during the current drought. The impact of the drought and its flow-on effects have had significant adverse bearing on the wellbeing of all community sectors, particularly for Aboriginal people.

RECOGNISED CONTEMPORARY LOSSES

The impacts of many of Australia’s historical policies inflicted upon the indigenous people include:

- The forced removal of Aboriginal children from their families – what we now know as the Stolen Generation;
- The assimilation policy – an explicit strategy of indigenous assimilation through forced removal of children from their family of origin and placement with Europeans. This was the most critical assault on Aboriginal social structures central to cultural practice.

We now know that important contributions to wellbeing lie in having a strong sense of personal identity, a sense of meaning in our lives and in being socially connected. In short, we survive and attain wellbeing through our conversations with others and those internal dialogues we have with ourselves.

UNRECOGNISED EMOTIONAL, HISTORICAL & CONTEMPORARY LOSSES

These are hidden amongst the recognised losses:

- Loss of one’s sense of identity;
- Separation anxiety;
- Unresolved grief and trauma are also inherited by subsequent generations (grieving for the mob);
- “Parents convey anxiety and distress to their children” (Prof. Beverley Raphael);



- Loss of a sense of self;
- Loss of a sense of power – feeling powerless to change a given situation/control;
- Loss of trust;
- Loss of confidence;
- Loss of self-esteem due to abuse inflicted on the children and adults as a result of their removal from families and the assimilation policy;
- Abuse: physical and emotional, mental and sexual. Physical loss may lead to emotional losses and these may create mental health problems later in life.

Local writer Jen Cowley and I have been connecting and presenting the workshops with communities and we are pleasantly surprised by the way it has been accepted. It seems we are helping people find a voice to heal through photography.

As a way of supporting communities and boosting morale, NALAG developed a photo storytelling workshop, Through Our Eyes. The workshop uses the medium of photography to enable people to tell stories and for emotional expression through the Aboriginal lens, literally. Participants are provided with digital cameras and are taken out “to go bush” or visit places or people that are important to them and then tell the story or find a word to express an emotion or an opinion of what the image means to them.

A recent participant remarked about the dry river bed at Brewarrina: The river has gone the place now looks unhappy, but you know, when I was a kid this place was the happiest place on earth for me.” The loss of water and the consequent degradation of the land seems to generate a deep sense of loss for Aboriginal people.

“We belong to the land and you know, when the land is sick we feel sick.”

The loss felt with the rivers drying up means that gatherings in traditional meeting places and fishing can no longer take place.

At Bourke, in the far west of NSW, another participant’s image expressed grave concern that the wildlife had gone, especially the birds as she felt a strong connection to birds. After the recent rain there was jubilation as the pelicans had returned. The rain generated a sense of hope and a promise that it will rain again and the so will the river flow again.

Finding a path to healing and discovering ways that are safe and acceptable to communities has been a priority for NALAG. NALAG was approached by REDI.E (an indigenous employment organisation) to provide workshops for their participants and the community to address loss and grief.



Photo Credit: D.J. Pauco



Photo Credit: D.J. Pauco



Photo Credit: Abigail Mawbey



Photo Credit: Abigail Mawbey



Photo Credit: Erin McGlynn

Thinking of getting involved?

How do I become a member?

It's easy! To become a member of NALAG, simply complete the membership form on our website. As a NALAG member, you'll be entitled to discounts on NALAG training and you'll receive a free copy of NALAG's Changes magazine.

How do I become a volunteer?

To become a Grief Support Volunteer for NALAG you will need to complete a basic training program approved by NALAG, then apply to become a member. It's that simple.

If you're not interested in grief support there are many other opportunities for volunteers

- writing, manual labour, graphics design, administration, catering - basically anywhere you can lend a hand when we need you.

What will you get in return? Hopefully the satisfaction of helping others in need, but you will also receive friendship and educational development opportunities.

More information about volunteering is available on our website www.nalag.org.au

The year that was

With Trudy Hanson, OAM NALAG CEO



TRUDY HANSON

CEO NALAG, Grief Counsellor and Educator

Trudy Hanson has more than 25 years experience in grief, loss and bereavement support and education. She is NALAG CEO and is based at the NALAG Centre for Loss and Grief in Dubbo. In her role she travels throughout remote areas of NSW to promote grief and loss awareness and education. She has a special interest in Indigenous grief and the grief experiences of infants and children.

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The past year has again been a hectic but successful, challenging but rewarding one for NALAG, with existing programs going from strength to strength and new projects and programs being added to the evolving stable of services offered to people and communities across NSW and the nation.

It is hard to express in words the impact of the work we do, or to adequately quantify the positive contribution NALAG makes. During 2018/19, the organisation conducted 3339 individual sessions and 92 group sessions along with 127 quality education and training workshops that were attended by 1418 participants.

We receive outstanding positive feedback from clients and participants, but beyond that we really never know the long-term impact our programs and sessions have made in people's lives, because this remains largely undocumented.

During this reporting period NALAG has moved into three new areas of operation to meet the

needs of the communities we serve. These have included programs to help address the impact of the drought; the loss, grief and trauma experienced by young people and in the provision of palliative care volunteer services.

To promote the additional activities NALAG conducts a Media Officer has been employed. Consequently, NALAG has been able to make a broader presence via the website and social media.

Drought events – bringing individuals and communities together to combat the impact of the continuing “big dry” – were held on 40 occasions, delivering to 4000 people feeling the effects of the drought across a wide section of NSW using innovative approaches.

In responding to an identified need to address youth issues, innovative education and youth focused programs were implemented in Phase 1 of the Youth in The Know program. In completing the three training programs offered, 138 Youth workers, teachers, school counsellors and mentors are now invested in delivering the three programs to young people in their

communities. In addition, 450 teachers and school staff received in-service training in their schools. Others were offered a more specialised workshop in complex mental health, which saw 41 people attend.

We have experienced strong growth in many areas, and additional funding received has allowed the employment of a clinical manager and two counsellors increasing our staff to nine.

In addition to our core funding from the Ministry of Health, I would like to acknowledge the financial support of Western PHN (Primary Health Network), Aruma, REDI-E, Mission Australia, Good Grief, VRA (Volunteer Rescue Association) NSW, and the Rotary clubs of Dubbo West and Macquarie. The financial support provided by these organisations and agencies has greatly increased our capacity to deliver education and support across NSW.

During the 2018/19 period we delivered a variety of successful education and training programs across NSW – 1418 people attended 127 workshops and education/training opportunities.

NALAG Centre continues to achieve and improve quality standards to retain our accreditation with ACHS, and I would like to acknowledge the hard work of our staff and volunteers who work hard to keep this important work up-to-date and ongoing.

I am grateful for the many volunteers who support the work of NALAG in numerous ways. Without our volunteers, NALAG could not exist. I would also like to acknowledge the contribution of the NALAG board, led by Julie Dunsmore, and the staff and volunteers of our branches who continue to make such a valuable contribution to the good work of the organisation.

Together we have accomplished many positive, collaborative and worthwhile achievements in order to enhance the wellbeing of those who have accessed NALAG following bereavement and other adverse life events.



BRANCHING OUT

NALAG NSW BRANCHES

Telephone Grief Support **Maria Holden, Coordinator**

The volunteers meet monthly for group supervision and training and this year we have also had additional trainings for our branch, with planning underway for next year's workshops and training of new volunteers. We are receiving registrations from various organisations in the community and have been asked to give talks at an aged care facility for their staff, residences and their families. Our client numbers continue to grow as we are becoming better known throughout the community.

Hunter Education Branch – by **Jenny Perino, Coordinator**

Hunter Branch was launched in August 2018 and has now been operating for more than 12 months. Membership is approaching 20, with volunteers being trained to support the extent of the region.

While there may have been a seemingly slow start, focusing on awareness and promotion, the Hunter branch also conducted two group responses with staff, clients and family following workplace suicide prior to the end of 2018. Similarly, Hunter was represented at the Seniors Health Expo at Old Bar with an excellent response following the presentation. The new year quickly picked up the pace, resulting in NALAG now being a recognised force in the Hunter region.

Throughout this year the Hunter Branch has conducted Loss and Grief training in Tea Gardens and Broadmeadow as well as holding community events in Taree, Gloucester, Stroud and Forster. Bereavement support groups are also conducted on a regular basis. The Hunter

branch has made great progress during this financial year and further education events are planned for the upcoming year.

Bellingen/Nambucca Branch **(Miindala) – Anna Bloemhard,** **Coordinator**

This year has been steady with extended face-to-face sessions, more one-off sessions and even more incidental support. Bellingen has had quite a few suicides, accidental and unexpected deaths and with this being a close-knit community, the support Miindala offers usually takes an incidental form.

The Suicide Bereavement Group, in conjunction with Lifeline, is continuing with Tony as the clinical director, and Miindala member Maggie as a co-facilitator.

A session for TAFE welfare students about grief and death was held by our co-ordinator who did a talk for HeadSpace about young people and grief, as well as a workshop on advance care directives, wills, enduring guardian and power of attorney. Two educational sessions with Lifeline and CHESS were held to talk about how to be with someone who is going to die, and there are regular sessions held for grandparents and drug support groups on the issue of grief and loss.

We have 14 volunteers on our books, some of whom are more active than others. We fast-tracked a few new volunteers who had the credentials but needed to know about Miindala and NALAG procedures.

Two biographies were successfully completed, however, we decided to shift the focus to helping people to write biographies for their loved ones or as an autobiography. We ran a few information sessions and held a workshop with 10 people attending.

The very successful One Year to Live program finished in March 2018, and a group of about 10 people continues to meet once every quarter year with Miindala support.

The Life and Death Matters expo in April 2019 was a great success, with good media coverage and great feedback from the public. Up to 150 people visited the expo which had a good balance of information, crafts, art and entertainment. Staff from Dubbo were present to offer ongoing support for Miindala.

Two "death cafes" were held with about 10-12 participants attending each. People appreciated the opportunity to talk about death and dying in a supportive environment.

The cooling plate is being used regularly as there is more awareness in the community of its availability. We now also have a cooling cuddle cot for babies (fundraising by Coffs Harbour Midwife club, Miindala and NALAG).

NALAG Mudgee – Ruth Gobbitt, Coordinator

Mudgee Branch has continued to grow and strengthen its connections in the community over the past year. We have a great team of 19 members, all of whom are very skilled in many and varied ways – some minding the centre, some supporting the team and 12 providing client support.

We have been involved with community groups such as talking about grief with CWA, helping Rotary with its open gardens weekend, supporting the community garden group and a disability service when they experienced sudden deaths.

We held a session with 28 train drivers for RUOK day and a remembrance ceremony in the park during grief awareness month.

One major event we held this year was becoming involved with the Department of Health in a pilot palliative care volunteer service to provide social support to those with a life-shortening illness.

Nine of our volunteers completed the training and we meet with our Palliative Care nurses monthly. We have slowly started providing this service to those in the community and we are hoping to grow this program.

Towards the end of 2018, we received substantial donations from Rotary, the Mudgee Chamber of Commerce and the Year 12 leavers from Mudgee High School. Six new members approached us to join as support volunteers. All these were unsolicited donations and we hadn't even been looking for new volunteers – we took this as a great encouragement that the community was now recognising and appreciating what we are doing.

In February, we established an advisory committee to help run the branch with an aim of broadening our profile in the community and providing free community training to empower all community members to be confident in helping those grieving or finding life hard for any reason. Drought needs no mention – we are all far too aware of the impact it is having across the whole community.



Youth in the Know

By Judy Scolari-Gibson Youth in the Know Program Co-ordinator

The Youth in the Know (YITK) program aims to improve the mental health and wellbeing of young people who have experienced trauma or distress because of loss and grief.

NALAG's role under this program is to provide evidence-based educational programs to assist with awareness and understanding of trauma for young people from the ages 10 to 18, utilising both primary and high school communities as the key stakeholders to best support the program framework. The program is funded by Western NSW Primary Health Network (WNSWPHN).

Training and workshops were delivered across 11 communities in the central west, western and far western regions of NSW during 2018/19, expanding this year to take in two more "feeder" schools to support students relocating from the western areas.

The YITK program contributes positively to students' wellbeing development and is building evidence towards free, effective training programs that can be delivered to school staff and their communities.

Our early YITK research and the pre- and post-training evaluations emphasised the need for evidence-based training to be delivered by accredited providers. This training also needed to be provided at an accessible location, relevant to participants' needs, and be new and informal in nature. Training also needed to provide teachers with the ability to gain credit towards their own professional development learning.

Three educational workshop/programs were offered as part of the program:

- Rock and Water – an experience that provides young people with a pathway to self-awareness, increased self-confidence and social functioning.

- Through Our Eyes – a hands-on, practical workshop that uses photo-interactive activities to enhance young people's self-knowledge, awareness and wellbeing.
- DRUMBEAT – a powerful and effective program for young people, incorporating hand drumming, behavioural therapeutic principles and cognitive and dialectical elements to strengthen the social and emotional skills for healthy relationships and values.

Accredited training days for facilitators were held in Dubbo and provided by Lighthouse Education (Rock and Water), Oracle Solutions (Through our Eyes) and Holyoake (Drumbeat). This was followed by an educational workshop on complex trauma by renowned Sydney-based psychologist, Philip Hilder.

"(The training) allowed the enthused participants to engage, learn and network with each other during the programs."

The delivery of training provided by these accredited Australian trainers allowed the enthused participants to engage, learn and network with each other during the programs. For those participants who lived more than 160 kilometres away, having their expenses covered allowed them to enjoy a stress-free opportunity to learn.

The majority of the participating schools referred two or three interested staff to attend from cross sectional staff positions from both primary and high schools. The external contracted trainers have also provided ongoing support. The overwhelming response to the training programs has exceeded the YITK program expectations with demand for training outstripping capacity. The development of a stakeholder's subcommittee across the 11 sites has assisted and contributed to the successful framework of the YITK program.

From the 153 participants registered, 138 (90%) attended all training and all returned the pre- and post-training questionnaires, and all supplementary resources were distributed to the trained facilitators who were committed to implement programs within their own settings. It was interesting to note from the post-evaluation that the participants' confidence level was high after training. This then enabled each location to start their group programs from Term 2 and 3 while training skills were new and confidence levels high. Each of the accredited trainers provided positive feedback on the organisation of the training events and the engagement and enthusiasm of participants who attended.

Eleven NALAG in-service educational sessions, which form Stage 2 of YITK, have been conducted within the sub region. These educational presentations were conducted by YITK Program Coordinator on request from school executives and trained facilitators of the YITK. These presentations were held as part of each school's staff professional development. To date 410 teaching and school staff have attended these educational sessions.

A 12-month evaluation follow-up was conducted across the sub regions stakeholders to which all participating sites contributed. This valuable feedback builds on the evidence for the program and future planning.

Due to the success of the program additional funding was received by WNSWPHN for 2019/2020 and the next five stages covering ongoing support and engagement are now being implemented. This will continue to build the stakeholders' involvement and encourage trained facilitators with capacity to continue and deliver individual and group programs back to their own community, as well as gather further evidence to assist youth who are experiencing distress.

**** Examples of the positive feedback from key stakeholders received during the first 12-month evaluation:**

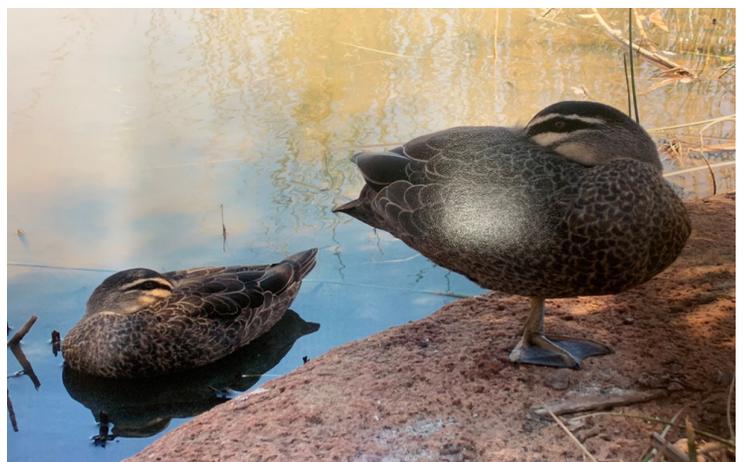
"You have removed the barriers to teachers gaining quality professional training".

"When the training has been paid for like this (it) makes it so much easier for my school approval to attend".

"This has taken training to the next level. It fits into what we need. It helps towards positive behaviour learning and within the wellbeing team framework".



Drumbeat participants with Holyoake Senior Australian Trainer Geoff Parker in Dubbo 2019.



"Looking within to find balance" E.H. (Through our Eyes) training in Dubbo 2019

Our Shout

Supporting communities through drought

With the drought's increasing and ever-tightening grip on communities across NSW, the NSW Health Ministry approached NALAG in 2018 to facilitate a program that would benefit and support individuals and communities impacted by the continuing "big dry".

As a result of extensive consultation with communities across the central, western and far western regions and in concert with other agencies and organisations working in the "drought space", NALAG developed a program called Our Shout, the aim of which is to assist rural communities experiencing loss and adversity as a result of ongoing drought conditions.

Coordinated by Brenda Baker, herself a farmer from Coonabarabran in NSW, this program involves consulting with local communities to ascertain what kinds of assistance would be of benefit and facilitating the events identified as helpful in promoting wellbeing.

Our Shout is a fluid program, adjusting and adapting to the changing emotional, social and wellbeing needs of individuals and whole communities as the impact of drought continues.

The success of the program lies to a large extent in the fact that it is community-driven – Our Shout responds to needs identified through consultation. The program conducts

activities and events that help promote positive strategies to enhance wellbeing and resilience in drought affected areas across the regions, while providing a combination of mental and physical healthcare support. The Our Shout program provides hope to drought-affected communities and actively demonstrates that recovery is possible.

The education component of Our Shout, in particular Farm First Aid which is held in partnership with Red Cross and other supportive agencies, has been particularly well received. Other programs and events have included a range of varied and diverse activities, all aimed at not only providing opportunities for social engagement to help reduce isolation, but at promoting resilience and engaging those in need with support services.

Some of the events held have ranged from family movie nights and ladies' "pamper days" to farm succession planning and working dog workshops. All these events have provided an opportunity for those impacted by drought to get together beyond the farm gate or business counter to share stories. Most importantly the program has helped to connect people within their own communities by affording them a chance to socialise and to put their worries on the back burner for a few hours. In the current and pervasive climate, this has been extremely important for helping individuals and communities to maintain a healthy mental state. During the 2018/2019 financial year, more than 40 events have been conducted across the regions, reaching an estimated 4000 people.

NALAG has also formed strong links with other organisations working to help people through the difficult drought period. Once every three weeks, a network of drought support workers from across a range of agencies and organisations, meets at NALAG to discuss upcoming programs as well as methods on how to assist rural communities.

This informal network – the Western Region Support Network – includes organisations such as the Department of Primary Industries (Rural Resilience Program), Centacare, Red Cross, Western NSW Local Health District, RAMHP (Rural Adversity Mental Health Program), Local Land Services, Interrelate, Marathon Health, Rotary, Rural Financial Counselling Service and St Vincent De Paul, Salvation Army and Rural Aid.



Brenda Baker and Jen Cowley at a rural community event for the Our Shout Program.



Trudy Hanson, Gerry O'leary and Brenda Baker attending the _____



Attendees at the drought support network meeting at NALAG in Dubbo.

Meet the Board



Julie Dunsmore AM – President

Julie has been working as a psychologist in the areas of loss, grief and trauma for more than 30 years. Since 2003, Julie has been the Bali Trauma Recovery Coordinator primarily working with NSW Bali Bombing survivors, bereaved and first responders; survivors from the Indonesian Boxing Day tsunami and most recently as a consultant for those working with the bereaved from the 2009 Victorian bushfires.

In 2008, Julie was invited to address the UN Supporting Victims of Terrorism symposium in New York and be part of the expert working group. Julie has had a special interest in working with bereaved parents, adolescents and children. She has worked extensively with those who have experienced traumatic bereavement after a sudden unexpected death, including suicide, murder and accidents. Julie conducts training in the area of psychological first aid, PTSD and complex grief treatment. She is well recognised for her innovative model of working creatively with those who have experienced trauma and grief.



Jen Cowley OAM – Deputy President

Jen is an award-winning former journalist, a published author, editor and trainer based in Dubbo, NSW. She is passionate about

community development, and has used her skills in communication and the media to work with communities both in Australia and abroad. Jen grew up on a farm at Coonabarabran and remains dedicated to promoting the wellbeing of individuals and communities in regional Australia. She is the author of *Grandpa's Hat*, a resource developed for NALAG to help guide children through discussions about death and dying. The book, published with the assistance of Rotary with all proceeds to NALAG, grew out of her experiences as a child, and later as a grieving adult, and is her way of saying "thank you" to NALAG. Jen has also worked extensively with Aboriginal communities throughout the western region of NSW and the Central Desert region of the Northern Territory, and as a Rotarian has been involved with humanitarian projects around the world. Jen holds a degree in English Literature, as well as qualifications in social sciences, business management and training.



Danielle Maloney – Treasurer

Danielle is the Deputy Director of the InsideOut Institute – Australia's first institute for research and clinical excellence in eating disorders. She holds an Honours degree in Psychology, a Master's degree in Public Health and an International Master's of Mental Health Policy and Services. Danielle has more than 25 years of experience in public health, the past 18 years of which she has spent working in the mental health sector. She has worked as a senior leader on clinical service redesign and clinical interventions across NSW to address early psychosis, personality disorder, eating disorders and clinical responses to trauma, abuse and neglect. Danielle has spearheaded the development of new and innovative health programs, such as Health Promoting Schools

(former President of the National Association), School-Link, headspace in central Sydney, and various NSW CAMHS clinical redesign projects.

She has led the design and delivery of research projects on clinical redesign, including the evaluation of the NSW Service Plan for eating disorders, the evaluation of the NSW pilot of the Assertive CAMHS service, and the evaluation of the NSW School-Link program. Danielle harbours a passion for child, adolescent and youth mental health, particularly early intervention and ensuring a client-focused, trauma-informed approach to the delivery of mental health services. Danielle is also passionate about redesigning systems and translating research into practice, to ensure clients and their families secure access to the best quality care possible.



Beate Steller

Beate Steller brings more than 30 years of experience in a variety of sectors to her role as a training consultant and spiritual care team leader. Beate has been an adult educator for the past 20 years which included being a training and development co-ordinator at the Centre for Community Welfare Training, Australian College of Applied Psychology, the Professional Development People, and Lifeline's (Sydney/ Sutherland) Telephone Counselling service as a trainer and telephone counsellor. Her experience includes working as a strategic planner and a community development officer at Sutherland Council, working with long-term unemployed and especially with people from indigenous and CALD (culturally and linguistically diverse) backgrounds. Beate's experience in the health services industry includes specialising in HIV AIDS, palliative care and aged care.

Her work has focused on working with organisations and individuals in the development of their goals, helping them to resolve conflicts, work through change and associated losses and developing a participatory approach in their work. In the past eight years, Beate has specialised in grief and loss education/ counselling and transition counselling. Beate has been on the board of

NALAG since 2009. She has both graduate and post graduate qualifications in adult education.



Kerry Frost - Secretary/Public Officer

Kerry joined NALAG in 2000 as a volunteer and served one term as President of the Dubbo branch. In 2004, Kerry accepted the position of secretary to the NALAG board. She has attained two diplomas, one in counselling and another in chaplaincy, as well as completing many workshops and courses in loss, grief and trauma during her time with NALAG. This has enabled Kerry to offer Grief support to a wide variety of clients. She considers her role as a "privilege and an honour" to serve with a highly skilled board that collectively has a passion for supporting people experiencing loss, grief and trauma. As a valued volunteer for more than 19 years, Kerry has contributed to the wellbeing of her community immensely, bringing her great satisfaction and joy.



Virginia Nicholas

Virginia has an extensive background working in education, having taught at TAFE for 30 years. She has been involved with NALAG since 2014 as a member and volunteer and became a board member in 2016.

Virginia is a valued grief support volunteer with NALAG's Mudgee branch, with a passion for helping those who have experienced loss and a strong belief that people should not walk alone.



Kaylene Green:

Kaylene has been a life long resident of Dubbo and has spent all of her working life so far as a Registered Nurse, initially working in critical care at Dubbo Health Service and for the past ten years as the Manager of Nursing at Lourdes Hospital and Community Health Service. Both of these areas of work have given Kay a keen interest in supporting people suffering through loss and grief. Kay joined the board of NALAG in November this year, 2019.



Jenny Perino

Jenny is a registered clinical counsellor and mental health practitioner who currently provides clinical supervision to NALAG staff and volunteers. However, she has a long association with NALAG having received her 20-year service medal which attests to her commitment to this service. A variety of Jenny roles have included establishing and chairing the Narromine chapter, serving on the state executive, occupying the position of state secretary, as well as working as a contracted counsellor and trainer. Most importantly, Jenny belief in tithing prioritises her volunteering component of this important work.

Jenny has lived and worked in rural remote areas for more than three decades and is credited with establishing the first Social Emotional Wellbeing Initiative for the Aboriginal Medical Services of the Bila Muuji (Upper Sector) and their seven communities. Similarly, Jenny established the first JIRT (Joint Intervention Response team) on Norfolk Island, in line with their newly implemented legislation for child protection.

Jenny has received an Australia Day Award for her

work on Norfolk Island and a volunteer medal from Doorways for mentoring homeless adolescents and young people.

Having worked extensively in rural remote settings Jenny now contributes as branch co-ordinator for the newly-established Hunter Region Branch.

The NALAG mission:
To strengthen the capacity of NSW communities and individuals to enhance wellbeing and promote resilience through support, counselling, education and advocacy following loss, grief, trauma and adverse life events.

Introducing....



Brenda Baker **Our Shout Rural Program Coordinator**

Brenda has lived and worked in the rural sector all her life, having grown up on her family farm just outside the small town of Junee in the Riverina region of NSW. Brenda studied nursing at Wagga University (now Charles Sturt University) and was chosen to participate in an Agricultural Exchange program in Canada, giving her the opportunity to immerse herself in small farming communities and experience Canadian rural life. This led to a lifelong passion for Brenda – living, engaging and thriving in small rural communities.

In 1989, Brenda and her extended family moved to Coonabarabran, beside the mighty Warrumbungles mountain range, to start a new enterprise for their growing families. Brenda nursed in the small town of Baradine for ten years and learned first-hand the struggles and joys of living in rural Australia. "Coona" has been the ideal place for Brenda and her husband to raise three beautiful children, all of whom have now flown the coop to make new adventures of their own. Brenda has continued her studies in counselling and is a volunteer for Lifeline as a crisis support worker.

As NALAG's Our Shout Program Coordinator, supporting rural NSW communities, Brenda brings warmth and knowledge to the position, and a profound level of empathy for those making a living in rural Australia. Her role involves helping communities to hold events and gatherings that are meaningful for them, while encouraging positive strategies to enhance wellbeing and resilience throughout rural and regional NSW.



Judy Scolari-Gibson **Youth in the Know Program** **Coordinator**

Judy joined the NAAG team in September 2018 as the Youth in the Know (YITK) program coordinator. She holds a Master's degree in counselling and has been working remotely in western NSW for the past 10 years for the Aboriginal Medical Services.

She has been providing counselling and support for families and individuals effected by the Stolen Generation policies. Her core area of work has been in domestic violence, sexual assault, trauma and providing court support. Establishing and running women's yarning groups and building lifelong friends and work colleagues in these communities has been one of her career highlights.

Judy has further studies in loss and grief and is a Louise L Hay, Heal Your Life trainer/facilitator. She also was a volunteer with NALAG from 2004 to 2007 back when she was beginning her study. In 2008, Judy was part of the team that submitted evidence to the federal government about the high rates of smoking within Aboriginal communities within western NSW and secured \$3m in funding following the submission. Judy worked as a tobacco treatment specialist under the auspice funding of Wellington Aboriginal Corporation Health Service and contributed to the reducing smoking rates within these clinics.

Judy previously worked many years for the local area health service within population

health as a program manager and part of the health promotion team.

She has a passion for improving inequality and social justice by having availability of social emotional wellbeing services within Aboriginal communities.

In her role with YITK Judy has accepted the challenge of improving the wellbeing of young people who have experienced trauma, loss and grief.



Andy Carolan Communications Officer

Andy joined the NALAG team in 2018 to assist with the organisation's growing public relations and communication needs. With a background in theatre production, Andy enjoys using innovative technology to improve NALAG's public presence and create positive experiences for all who interact with the organisation. Andy works closely with a broad range of media agencies and channels to ensure information about our services, events and training opportunities is distributed effectively and efficiently. He holds a strong interest in storytelling and videography and his acquired skills help to provide a fruitful medium for the organisation to connect, support and share with NSW communities, families and individuals.

The exponential growth of social media and other communication technology – predominantly digital – has in recent years created an unprecedented need for service providers to step outside the traditional mediums of communication. Although still important, issuing press releases makes up only a fraction of successful modern-day communication strategies. As a largely government-funded organisation, it's crucial that the people of NSW are aware of NALAG

and the services we offer. It's equally important that we make our organisation as accessible and approachable as possible.

With the expansion of the organisation late last year, NALAG established the position of Media and Communications Officer to ensure its public presence and relations were maintained and enhanced, recruiting Andy to the team.

Working closely with the CEO as well as with the branch and program coordinators, Andy is responsible for the effective distribution of information from NALAG to the communities, families and individuals we work to support. This includes incorporating new communication methods and embracing the "cybersphere" as a constantly evolving medium for social interaction and communication. The internet has become a vital source of news, information and resources for many people, particularly those living in isolated communities.

In 2019, NALAG's new website was accessed more than 13,000 times. People now have access to helpful tools and resources from the website from anywhere at any time, without necessarily needing to speak to a team member.

This "online" service is proving extremely efficient, however its success depends heavily on how well we connect with new audiences and maintain our reputation as a leading service provider throughout the state.

To address this, Andy has worked to improve the organisation's overall branding and public appearance, and created digital "shopfronts" on social media platforms such as Facebook and Instagram.

By establishing a strong presence on these platforms, we have boosted public awareness of NALAG and enabled an alternative pathway for people to contact us. As a result, NALAG's subscriber base has tripled in the past 12 months and our 2019 programs and events have been extremely well-attended. More and more people across the state are recognising and engaging with our organisation. Achievements in communication will continue to be a major aim for NALAG in 2020 and beyond.

As technology advances, NALAG will adapt and evolve to ensure we remain a well-known and accessible service to the people of NSW.



Fond Farewell

New Pastures for Shelley Carolan

It was bittersweet for all the NALAG team in October this year to bid farewell to friend and colleague, Shelley Carolan, who, after much soul searching, made the decision to take a change in her life's direction and step down from her role as the organisation's Intake and Support Volunteer Co-ordinator.

While we are all happy for Shelley, we can't help but feel sad to wave her goodbye as she sets sail on new adventures.

Shelley has been an integral cog in the NALAG wheel for many years, first stepping into the fold as a volunteer and then as a valued staff member, an association that has totaled some 15 years on and off (after a brief hiatus, Shelley returned to a paid position in 2017).

Over the years, the vibrant Shelley has been a recognisable and trusted member of not only NALAG but the community it serves, and was in 2017 awarded the VRA (Volunteer Rescue Association) Service Medal after 10 years of dedicated service.

NALAG CEO, Trudy Hanson, described Shelley as "an all 'rounder" – an excellent communicator and an empathetic grief support volunteer. She represented NALAG at countless promotional activities and, back at her desk, was an extraordinarily proficient administrator.

Shelley's work with helping to develop and promote NALAG's Blue Healers program was one of the hallmarks of her time with the organisation, and as a senior Blue Healers facilitator for more than ten years, her dedication to this program and its success and effectiveness will long be one of her legacies. Also trained as a Seasons for Growth Companion, Shelley enjoyed working with

children and young people and was adept at gaining their confidence and trust. She was also an effective trainer in the Seasons for Healing (Aboriginal loss and grief education) program and travelled to many remote communities with the NALAG team, helping to facilitate the program.

Board president, Julie Dunsmore, spoke not only on behalf of her fellow board members but for all the NALAG team in acknowledging Shelley's great contribution over so many years.

"The kindness, compassion, professionalism and care Shelley showed to all those who made contact with NALAG has been exemplary, and I know the volunteers in particular, will miss her terribly."

We all join with Julie in echoing that gratitude and expressing our best wishes for whatever lies ahead for Shelley.



Rotarian Sally Coddington, Trudy Hanson, Shelley Carolan.

and express those emotions in very different ways.

At NALAG our aim is always to ease the path for those who are facing and struggling with loss and grief, which comes in many forms. Finding a way to express feelings of loss, grief, anger, sadness, frustration – and yes, joy and happiness as well – is important to overall mental health and wellbeing.

Taking photos can be a very effective way to communicate feelings and can help in the grieving process – by letting the pictures do the talking when words just aren't enough.

Each year, more and more people take part in NALAG's photo treasure hunt, and they represent a diverse range of demographics, coming from right across the age, gender, ethnic, ability and social spectrum. We are very proud of not only the way in which the event helps to bring greater understanding of the value of creative expression in managing emotions, but of the way in which it brings people together.

Throughout this edition of Changes, we are sharing some of the wonderful entries we received this year for the photo treasure hunt, the themes for which were: strength, support and share.

Congratulations all those who took part and to the 2019 winners:

1st SENIOR CATEGORY: Mandy Edwards

1st JUNIOR CATEGORY: Amy Gore

2nd SENIOR CATEGORY: Jody Turner

2nd JUNIOR CATEGORY: Millah Bush

3rd SENIOR CATEGORY: Annette Ferguson

3rd JUNIOR CATEGORY: Erin McGlynn

PEOPLE'S CHOICE: Lyndsay Kohlet

HIGHLY COMMENDED: Lucy Gibson, DJ Pauco, Emily Stuart, Abigail Mawbey, Clancy Judd, Grace Vaile

A Picture Paints a Thousand Words

Sometimes, it's hard to express your feelings in words.

Many people find it easier to communicate how they feel by doing a painting instead... or taking a photograph. Photos can be very effective in telling a story –

your story, someone else's story, any story.

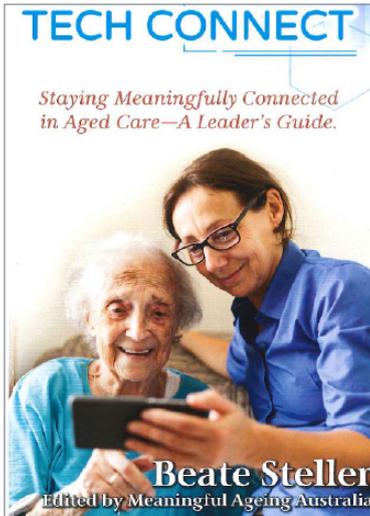
The positive and growing response to NALAG Dubbo's annual photo "treasure hunt" bears testament to this notion of using the creative exercise of photography to express emotion and tell a story.

Run over the course of a full Saturday, the treasure hunt begins early in the morning when community members are invited to register (free of charge) at the NALAG Dubbo centre where they are given a set of three single "theme" words. They then take photographs throughout the day that they feel best reflects those words and the overall theme, and return to the centre late in the afternoon where the photos are downloaded and printed. NALAG staff and volunteers then arrange the images for an exhibition at which guest judges select the set of photographs they believe best communicates the theme, and the participants and

The object of the exercise is not to judge photographic technique, but to encourage community members to understand the value of expressing their emotions – of all kinds – through creative pursuit, in this case photography. It is also a valuable illustration of the way in which reactions and perceptions can vary – how people might experience the same thing, but exhibit a diverse range of emotions

Resources

Books



Tech Connect **Author: By Beate Steller**

(Photos: cover and Beate with 87 year old Pat, about whose experience the book is written.)

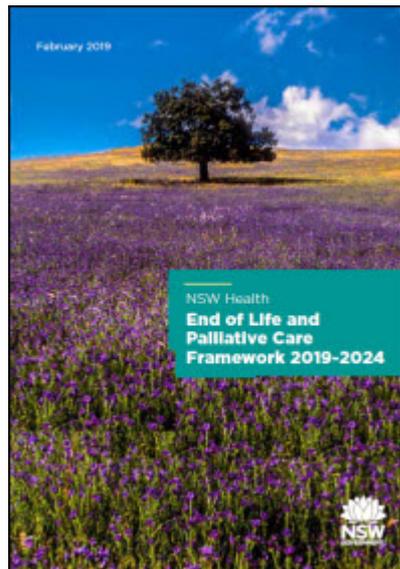
Beate Steller is a member of the board of NALAG and has written a book called Tech Connect.

“Pat was devastated. The 87-year-old, who had been living in aged care for the past seven years, had experienced a recent change in health and was now receiving palliative care [in the south of Sydney]. She realised that she was too frail to travel to Melbourne for her grandson’s wedding.”

Beate Steller, a spiritual care practitioner at Pat’s aged care home, was able to support Pat to virtually attend her grandson’s wedding, along with the whole community!

Maintaining connections with friends and family is a vital aspect of living a meaningful life. Tech Connect is a guide to supporting these meaningful connections, using person-centred care alongside social media and other communications technology. Tech Connect is for aged care professionals who are passionate about supporting the emotional and spiritual needs of older people in their care.

The book is available through Meaningful Ageing Australia at <https://meaningfulageing.org.au/product-category/hardcopies/>



Education, Training & Events

Education & Training

NALAG offers a range of education and training throughout the year.

- Stormbirds Companion Training
- Blue Healers Depression Program
- Seasons for Growth Companion Training,
- Seasons for Growth
- Loss & Grief Volunteer Support Course
- Plus so much more

Annual Events

NALAG has a range of promotional and awareness events throughout the year including:-

- Grief Awareness Month (annually in August)
- Walk Towards Hope - Suicide Prevention Awareness Walk (annually in September)

Monthly Events

**@ the NALAG Centre for Loss & Grief
Dubbo - Welchman St, Dubbo**

Mates of NALAG Morning Tea

The Mates of NALAG Morning Teas are held on the first Tuesday of the month at 10.00am. A men's group of friends of NALAG, this is an opportunity for anyone with a connection to NALAG or in need of friendship to come to the centre and catch up over a tea or coffee.

**@ the NALAG Centre for Loss & Grief
Mudgee - 107 Mortimer Street, Mudgee**

Yarning Group

The Yarning Group is for people who like to work with yarn (knitting, crochet etc) or for people who like a yarn (chit chat, natter etc) to come to gether in friendship and companionship.

Held at 10.00am each third Tuesday of the month at the NALAG Centre in Mudgee.

More information

For more information on any of these events please see our website www.nalag.org.au or follow us on social media.

You can also call the NALAG Centre in Dubbo on 02 6882 9222 or NALAG Centre in Mudgee on 0488 255 710.

NALAG also provides customised training to organisations based on need. Contact us for more information.

Bookings & Enquiries

NALAG Centre for Loss & Grief Dubbo

Ph: 02 6882 9222

E: education@nalag.org.au

www.nalag.org.au

Social Media

Keep up to date with NALAG on social media, particularly Facebook and Instagram.

