Welcome to the fourth edition of our new publication, Bereavement Practice in Palliative Care.

In this issue, Melbourne Oncologist, Dr Ranjana Srivastava, has contributed our feature article: Communication in Palliative Care. This article looks at the importance of good communication around end of life discussions with patients and their families. Communicating with a patient’s family prior to a death can be challenging, however skilful and collaborative conversations can have a major impact on a carer’s grief experience. I encourage you to reflect on your practice in this area and consider ways that we can continue to improve our communication with families and carers.

Alongside the feature article, we have also included an interview with a palliative carer; a client handout looking at grief and anxiety; and a book review of Dr Srivastava’s book, Dying for a Chat: The Communication Breakdown Between Doctors and Patients.

I’m also delighted to announce the 2014 Australian Grief and Bereavement Conference. This dynamic professional development opportunity will bring together five world-class keynote speakers, alongside local presentations, pre-conference workshop opportunities and social networking events.

The Conference will take place at the Bayview Eden Melbourne (26th–28th March 2014) and will take the theme Bridging the Gap Between Research and Practice. I encourage you all to consider attending this conference and invite abstract submissions from anyone with an interest in the bereavement field, who would like to share their research and practice findings. For more information about the Conference, please go to www.grief.org.au/conference

Christopher Hall,
Director, Australian Centre for Grief and Bereavement
Communication in Palliative Care

By Dr Ranjana Srivastava, Medical Oncologist and Author

Most of us work in the healthcare profession because we want to make a difference. It is a sentiment expressed equally by the aspiring medical student, the veteran nurse, the ward clerk and the retiring professor. But how to make a difference is the question.

Once upon a time my mind was abuzz with the question of how to be a doctor who made a difference. Like my peers, my initial concerns centred on mastering the facts, which was a continuation of what life had been like as a medical student. As a budding oncologist there was no lack of chemotherapy protocols and statistics to challenge my every step and usually fill me with the dread that I would never quite find my feet. I was convinced that everyone would always know more than me and would be better than me. Better, of course, had a narrow definition for me at the time — it meant a strong grasp on the science of medicine.

But as the years progressed, I discovered a side of medicine that had less to do with the science and more to do with its art. One Friday evening, I was called urgently to the bedside of a man incidentally diagnosed with lung cancer when he presented with appendicitis. The referring team had panicked at the news, infecting the family and me along the way. I remember jabbing at the elevator button with a senior oncologist at my side. I thought of all the urgent things we needed to do — chart his chemotherapy, send off more tests, locate a bed on the oncology ward and so on. But the oncologist shared none of my rush. If anything, he seemed complacent and I daresay, disinterested, as my story unfolded. When he finally spoke, all he said calmly was, 'Sometimes the hardest task is to do nothing except take the time to talk to people.'

At the patient’s bedside, everyone was in a state of shock. The patient’s wife was sobbing and her adult children were standing by the bedside quietly holding their father’s hand. When we introduced ourselves, the patient’s first question was, ‘When am I going to die?’ What followed was a salutary lesson in my life. The oncologist pulled up a chair and invited everyone else to sit down. ‘I recognise that you have just had some bad news. I am here to make sense of it with you and give you all the time you need to ask me questions.’ The family who was half-expecting us to walk away from their obvious distress looked instantly relieved at the offer. We spent the next forty minutes discussing anything that came to their mind. There were practical questions such as what treatment was feasible, when it might start, and what the side effects might be. There were questions about logistics — about whether they should cancel their overseas trip and bring forward a family wedding. There were also existential questions — the ‘why me’ and ‘why now’ kind.

I watched in silent admiration. The first thing I noted was the oncologist’s patience. His body language and expression suggested that he had nowhere else to be but with that patient and that family. This had the instant effect of slowing down the family’s tumultuous thoughts. He stopped often and checked for understanding. At that early stage he didn’t have all the answers but he was honest about what he knew. He told them that the lung cancer was inoperable but modern treatments were beneficial and that occasionally, patients stayed well for a long time. I noticed that while this did not promise the patient an unrealistic cure, it also did not consign him to a life without hope. This is the tightrope that many of us shudder to walk.

Recognising the family’s fears about navigating the journey ahead, he reassured them of our team’s experience, attention and commitment to his wellbeing. It was instructive that he did not shoulder the entire responsibility for the patient but invoked the team nature of caring for him. Many of us feel inadequate caring for all the needs of the patient but we can rely on our colleagues while we do our job well.

When the family apologised for asking so many questions the oncologist normalised their experience by telling them that he would have reacted in the same way. He sympathetically advised them that there would be more periods of uncertainty but support was available. He asked them to use these resources without hesitation, reminding them that they were not being troublesome.

All these years later, I still remember that conversation. Here was an oncologist who recognised the place of empathy and compassion early on to smooth the road ahead. He understood that there are key conversations we have with patients that have the power to shape their experience, and it is worthwhile...
to treat these conversations with the respect and seriousness that they deserve. When we walked out that night I knew that the oncologist had made a profound impression on the patient and the family and rescued them from the verge of despair. And although they would almost certainly find themselves in a tough place again, they would be consoled by the memory of his words.

We sometimes come to regard these humanistic traits as either not terribly important or intrinsic to those individuals who just seem to have the right touch. We feel this might absolve us from developing better communication skills provided we are good at our so-called ‘core business’, which may be performing surgery, prescribing chemotherapy or rehabilitating patients. Except, our patients repeatedly tell us otherwise. They tell us that what matters as much as safe and timely treatment is how we treat them. Patients want to be treated as human beings, with dignity, humanity and respect. Having an illness does not dilute these desires.

There are some sentinel moments in the lives of our patients when our gestures are particularly significant. How you break bad news, stop active treatment, hold a family meeting or have a discussion about end of life care are very important conversations in the lives of not just the patient but also the whole family. Families remember how we treated them long after the patient is gone. Our communication has a lasting impact on how people grieve.

No one feels like a natural giving bad news when it is so much nicer to share in the success of our endeavours. But as our population ages and we are faced with more and more complex, chronic diseases, we will all need to be better communicators. The science is important, but so is the art of medicine.

The good news is that we can all get there. We need to start with believing that we owe this much to our patients.

Dr. Ranjana Srivastava is a medical oncologist and the author of two books. ‘Tell Me The Truth: Conversations with My Patients About Life and Death’ and ‘Dying for a Chat: The Communication Breakdown between Doctors and Patients’. She is a regular contributor to the Melbourne Magazine on matters of humanity in medicine.

To read more visit www.ranjanasrivastava.com

Further Reading:

Grief and Anxiety in Palliative Care

When someone you know is dying, it is common to experience grief both before and after the death. ‘Anticipatory Grief’ is when we start grieving the death of our loved one, before they have died. We grieve the impending loss, not just of them physically, but also the loss of their presence within our lives — loss of their dreams, their future.

Anxiety may occur within the experience of anticipatory grief. You may become anxious about whether the person is comfortable or in pain, whether they are scared, anxious, or whether they will die when you are not there. You may feel anxiety around the loss of a companion, changing roles in the family, changes in their appearance, or financial changes. These are all very normal feelings, but can be debilitating and leave you feeling helpless, exhausted, angry or frustrated.

Common Symptoms of Anxiety

Common symptoms of anxiety may include:

- Feelings of distress, panic, apprehension, dread and uneasiness
- Tightening of the chest, or chest pain
- Racing heartbeat
- Hot and cold flushes
- Constant and repetitive worrying
- Obsessive thinking, e.g. having the same thoughts over and over again
- Compulsive behaviour
- Changes in eating habits
- Shifts in breathing

What Can Help?

Fear and anxiety are normal emotions that we all feel from time to time; however, when these feelings become excessive, overwhelming, distressing or begin to interfere with daily life, you may need to seek further support.

If you are concerned about your anxiety, either before or after the death of a loved one, it is important to seek professional support from your GP, health professional and/or mental health practitioner (e.g. counsellor, psychologist).

Things you can do yourself that may help you include:

- breathing – deep, slow and focused, especially in the lower abdomen, as this refocuses the energy of the anxiety and grounds you back into your body
- writing things down or journaling
- talking to a friend or family member about what you are thinking or feeling
- relaxation activities e.g. sleeping, listening to music, massage, meditation
- physical activity – even taking a short walk around the block can be helpful
- eat a balanced and healthy diet
- try to reduce the amount and frequency of stimulants such as caffeine, alcohol and tobacco
- attend a support group, or online forum
- seek help from a GP, counsellor and/or mental health practitioner
- find out more – increasing your understanding of anxiety can help increase your sense of control.

Further Information

BeyondBlue
www.beyondblue.org.au
Sane Australia
www.sane.org.au
Anxiety Disorders Association of Victoria
www.adavic.org.au

For further information on grief and bereavement visit www.grief.org.au
Love yourself and the one who is dying... It’s about being able to allow the person who is dying to make choices about how they want to die.

Interview with a Palliative Carer

The interviewed carer wished to remain anonymous.

What experience has brought you to this interview?

The death of my wife of 55 years in October 2012.

What were the most challenging aspects of your role as a carer?

Watching my wife die. Everything else was peripheral. It was a death sentence and I watched it being executed. We both had no fear of extinction, as we believe the soul is immortal, but physically watching her die was hard. Watching her pull out the nasogastric tube was also challenging as leaving it in would have prolonged her life. Pulling it out meant she had 5-6 days to live. I remember it vividly. She took responsibility for herself to the ultimate point.

What were the most rewarding aspects of your role as a carer?

That my wife could be at home and that I could make her comfortable with myself and her family nearby. I was able to get her out of hospital and had the option to be with her and care for her at home. Palliative care at home is a brilliant service.

What were some of the most helpful supports or resources you received from palliative care workers?

The availability of palliative care staff 24/7 was very reassuring. I didn’t have to talk to an answering machine and be told to ring between office hours. The palliative care nurses made sure I understood how to administer the medication, and were also able to verify the death and call the funeral home so I didn’t have to be making phone calls and organising things straight after she died. The grief counselling was profoundly important too.

What advice would you give someone who finds himself or herself in the role of carer?

1. Ask for support from family to enable yourself to have some time out. Having this time will give you more energy to handle it.
2. Eat good, healthy meals on a regular basis and get sleep. If I hadn’t had good sleep I would not have been able to last the distance.
3. Love yourself and the one who is dying. Don’t go into a pity party as it aggravates the condition. It’s about being able to allow the person who is dying to make choices about how they want to die. If I was acting out of fear instead of love I would not have been able to allow her to take the nasogastric tube out which was her choice.
4. Don’t beat yourself up with guilt.

How has your life changed since the death of your wife?

I have had a great sense of loss — of a partner of 55 years. I have felt relief as she no longer had to suffer and her soul could rest. I have felt the freedom to establish a new life for myself, resulting in me forming a new relationship, establishing a new life and a whole new set of experiences. My wife and I had talked about how life would change after she died. She made me promise her that I would not feel sorry for myself and be a victim but I would get out and about and meet people, be with friends and form new relationships.

Have you felt supported in your grief experience?

I have felt very supported, particularly by my family and friends and by my bereavement counsellor. The people I spoke to honoured me with listening and I was able to speak deeply about how I felt, which helped me overcome my sense of loneliness. Being able to talk about my grief to people who weren’t just trying to fix it, was very therapeutic.

What are some ways you have engaged in self-care since the death of your wife?

I have gotten out and about, going out to live theatre and to dinners with friends. I asked people to spend time with me and I ate and slept properly. Even though through my grief I have had a sense of a huge loss, it has also given me a sense of what do I do next? I can’t expect other people to fill that gap; you have to fill it yourself. I have allowed myself to experience my grief but also allowed myself to live.
Our Services

Bereavement Practice in Palliative Care
For all enquiries about this publication, please contact Jenny Field on (03) 9265 2100 or email j.field@grief.org.au To download a PDF version, or to sign up to receive the publication as an e-newsletter, go to www.grief.org.au

Bereavement Counselling and Support Service
The Australian Centre for Grief and Bereavement (ACGB) operates a statewide Specialist Bereavement Counselling and Support Service for Victoria. This program is supported by the Victorian Government Department of Health and has counsellors located across metropolitan Melbourne, in regional areas (Grampians, Gippsland, Hume, Barwon South-West, and Loddon Mallee) and in areas affected by the 2009 Victorian Bushfires. For further information, call (03) 9265 2100, or email counselling@grief.org.au

Support groups
ACGB operates a range of support groups, including groups for adults, children, bereaved partners, loss of a parent and many more. For further information call (03) 9265 2100 or email support@grief.org.au

Practitioner Consultancy Service
This service provides free information, consultation and support for practitioners who are working with bereaved clients experiencing complex and prolonged bereavements. To access this service call 1300 858 113 during business hours.

Education and training
ACGB offers quality education and training opportunities for health professionals, students, volunteers and any other individual or agency desiring to enhance grief and bereavement knowledge and practice. Education and training programs are offered as seminars, workshops, short and long courses, conferences and customised training. For full details of all programs and services offered go to www.grief.org.au/education

Australian Grief and Bereavement Conference 2014
Taking place at the Bayview Eden Melbourne from the 26th–28th March 2014, the Australian Grief and Bereavement Conference is a professional development opportunity not to be missed! For further information and to register go www.grief.org.au/conference

Customised training and consultancy
ACGB offer a range of customised training and consultancy services that provide research-informed, high quality, professional development programs that meet the specialist training needs of organisations, groups and individuals. For further information contact the Centre on (03) 9265 2100 or email education@grief.org.au

Grief Matters: The Australian Journal of Grief and Bereavement
Published by ACGB three times per year, this journal encompasses both academic and applied aspects of grief and bereavement and is a ranked journal with the Australian Research Council as part of the Excellence in Research for Australia (ERA) initiative (www.arc.gov.au) To find out how you can subscribe to this journal, call (03) 9265 2100 or email griefmatters@grief.org.au

Internships
ACGB has a limited number of placement opportunities for experienced counsellors seeking to advance their knowledge and skills in bereavement counselling. For further information contact the Centre on (03) 9265 2100 or email info@grief.org.au

Membership
Access a range of benefits through the ACGB membership program. An enhanced membership option, reciprocal membership with the Association for Death Education and Counseling (ADEC), is also available. For more information about membership options and benefits go to www.grief.org.au/get_involved or call (03) 9265 2100.

Donations
Donations over $2 are tax deductible and allow ACGB to continue to provide services including bereavement counselling, support groups, newsletters, events, education and training. To make a donation, visit www.grief.org.au or call (03) 9265 2100.

We value your feedback
If you have feedback about this publication, or any of the services delivered by the Australian Centre for Grief and Bereavement we’d love to hear from you. Contact us on (03) 9265 2100 or email info@grief.org.au

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