IWG NEWS

Latest News and Updates for Members & Friends

February 2024

The Healing Colours of Country: Trauma recovery through culture, art and wildflowers, a multilayered collaborative triptych created in the Healing Hub at the 2nd National and World Indigenous Suicide Prevention Conference in Perth Western Australia in November 2018

Philip Larkin

IWG Board of Directors

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Message from the Chair

Dear members, colleagues and friends,

This is my first report as Chair of IWG and I know that some of you will know me better than others so probably a first point of order is to tell you a little about me.

I am from Ireland and a nurse, having worked in palliative and end-of-life care as a clinician and academic in this field for about 38 years now. I was previously Chair of the All-Ireland Institute of Hospice and Palliative Care, a foundation set up following the Good Friday agreement based on the principles of human rights and social justice. Latterly, I was President of the European Association for Palliative Care (EAPC 2015-2019) and have had the privilege to work and teach across the world in many varied capacities.

I have been a member of IWG since Vancouver 2014 and was part of the 'Celtic' organizing committee for the Dunblane meeting in 2016. In 2018, I moved to Lausanne in Switzerland where I am the Christian Gerhard Chair in Palliative Care Nursing, based in the palliative and supportive care service of Lausanne University Hospital and Full Professor in the Faculty of Biology and Medicine at the University of Lausanne.

I bring these skills and expertise to the role of the Chair and hope I can use them to serve you and the organization to the best of my ability in the months ahead.

A new board for IWG

As you know, board elections took place just before the Halifax meeting and it is my pleasure to ensure that members know who the elected representatives are.

I would first like to pay tribute to my predecessor as Chair, **Dr Inge Corless**, for her ongoing commitment to the vision of IWG and steering us through the challenging waters of moving from Australia back to the US and all that entails in terms of administration, paperwork and headache. Inge remains on as a board member and a source of wisdom from which I can draw. **Thank you, Inge, for your support.**

I would also like to thank the members of the previous board, two of whom have stepped down: **Regina Syzlit**, Vice-Chair, and **Stephen Connor** and two whose term of office has come to a close, **Ruthmarijke Smeding** and **Donna Schuurman,** for their rich contribution to the work of IWG.

Dr. Darcy Harris, London, ONT, Canada

Dr. Andy Ho, Singapore

Dr. Inge Corless, Boston, Mass. USA

Ms. Val Maasdorp, Harare,Zimbabwe

Our new board is as always, a mixture of the older and wiser (no insult intended!) and the new. Those who can provide continuity of the work from the past and those who may have new innovative and thought-provoking suggestions for the future.

Of course, you will immediately recognize that the "new" board are hardly that; most (with the exception of me!) have been longstanding members of the IWG and so we have a lot to offer in terms of leadership and organizational wisdom. I would like to thank them all for standing for election and for the members in giving us the mandate to represent you to the very best of our ability.

A change of Secretary/Treasurer

As you know, **Jim Monahan** stepped down from this role in December. I want to take this opportunity to thank Jim for his work in managing the day-to-day administration of our business, both organizational and financial which involved a wide range of responsibilities including management of the website. Finding a replacement has not been easy but I am delighted to confirm that **Chris Hall** has agreed to take back some of the substantive duties of the Secretariat until our next meeting in Perth (see **Lauren Breen's** post for more details).

We are exceedingly grateful for his stepping forward to help us keep on track. It is really appreciated.

To support the work, I would also like to announce that **Janet McCord** has agreed to take on a role as Minutes Secretary with the board, to help prepare the meetings and make sure all runs smoothly, and we have accurate records of business. Again, we are grateful for Janet's support.

Having delivered the good news, I would remind you that these are interim solutions until Perth and we will be looking for a more permanent solution from then (I will be coming back to you….).

A particular welcome to our new members

I am delighted to inform you that seven member candidates were successfully approved for full membership after the Halifax meeting (see below) and on behalf of the board, we welcome them to the IWG family and wish them a fulfilling and engaging collaboration in the years to come. We are seeing a shift in those applying for membership to more practice orientated roles and less pure academic roles as in the past. This opens opportunities for new and exciting collaborations and new visions for IWG in its scope and vision.

Congratulations to: **Tammy Bartel, Tashel Bordere, Deanna Hutchings, Daisuke Kawashima, Bianca Lavorgna, Carla Sofka** and **Barbara Thompson.** Welcome!

Halifax 2023 – another really successful meeting

Many of you were able to attend the 33rd meeting of **the IWG in Halifax, Nova Scotia in October last year.** As always this was a wonderfully rich and fulfilling meeting, an opportunity to reconnect and engage with colleagues and friends and previous work and workgroups. As I imagine everyone knows at this point, we were unfortunately struck down by a dreaded surge in COVID infection which led to some last minute arrangements and changes as the week progressed and I would like to thank all of you who contributed to support those of our members who succumbed to the infection by ensuring they were fed and watered and kept abreast of the changing information on how to manage their symptoms.

However, the main accolades go to the Halifax Planning Committee who were so welcoming and made sure we enjoyed true Canadian hospitality. The venue was excellent, the food amazing and not least the entertainment for the gala dinner at the Canadian Museum of Immigration led by a Salsa band through the streets of Halifax.

The Board wishes to extend our personal thanks to **Susan Cadell, Mary Ellen McDonald, Phil Carverhill** and **Betty Davies** for a job well done and despite our Covid moments, we offer our sincere gratitude for all that you did to welcome us to your beautiful part of the world.

Those we remember

It would be remiss of me not to mention that since my appointment, a number of longstanding and founding members of IWG have died and although it has not been the practice in the past, I felt it was important to note it here. We extend our deepest condolences to the family and friends of **Connie Goldman**, **Dr Thelma Bates** (whose memorial will take place on March 18th at the Royal Society of Medicine Wimpole St, London W2- rsvp to **Ms Joanna Rose** at rsvp@rsm.ac.uk), **Professor Joachim Wittkowski** who died very shortly after being with us in Halifax and last but by no means least, **Professor Colin Murray Parkes**, for whom tributes appear later in this edition of the Newsletter as well as information on the Scholarship programme. We will remember them formally at our next Time to Remember meeting in 2025 but we hold them in our thoughts with heartfelt thanks for their contribution to the world of IWG and death, dying and bereavement overall.

Some thoughts on next steps

As Chair, my job is to respond to the needs of the organization and work with the Board to make sure that we make change where it is needed and secure the governance and financial stability of the organization for the next generation of IWG'ers.

The vision of IWG is clear as are the by-laws (more or less) but we need to do some work on policy and procedures to help the board manage the various roles and functions better and respond more quickly for effective decision-making. We are developing a policy and guideline committee to help work on this aspect and make sure that we have a clear line from the by-laws to policy to practice and so reduce the overall burden of work on the Secretariat in managing these elements.

Other committees, such as the publications committee, will be resurrected in 2024 (possibly with new terms of reference) to make sure that visibility of IWG in the promotion of scientific excellence in the area of death, dying and bereavement is achieved. However, we are open to your ideas and if there is something that you feel would be of benefit to members and the organization as a whole, please let us know. For now, we will focus on making sure that IWG is on a secure footing from a governance perspective.

We are here to serve…

So, in closing, I hope that I and the board can serve the membership to the best of our ability. My door is always open. If there are things that you think need a revamp or change or indeed things that have gone well and you want to make sure we do not lose sight of, let us know. As this is the first Newsletter for 2024 I would like to extend our profound thanks to Irene Renzenbrink for her contributed excellent editorial services. We look forward to an exciting and innovative year ahead.

With kindest wishes and on behalf of the IWG board,

Phil Larkin, Chair.

your contact is welcome at philip.larkin@chuv.ch

Lauren Breen, Chair of Perth IWG Planning Committee

Members and Supporters of the Perth Planning Committee also include:

June Allan

Julie Edwards

Meg Chin

Chris Hall

Liz Lobb

Mal McKissock

Dianne McKissock

Danny Nugus

Irene Renzenbrink

Dear IWG friends,

Kaya!

This means hello in Noongar language. We are beyond thrilled to announce that the 34th meeting will be in Perth, Australia!

Perth is located in the ancient land of the Whadjuk people of the Noongar Nation who have been the Traditional Owners of the southwest of Western Australia for over 50,000 years. As a meeting place for thousands of years, it is especially significant that Perth is the destination for the **34th Meeting of the International Work Group on Death, Dying and Bereavement in 2025.**

Perth, on the west coast, is Australia's sunniest capital city and sits on the banks of the sparkling Swan River boasting the world's largest and most beautiful inner-city park. You are only ever footsteps away from nature. Western Australia's size –almost 4 times as large as Texas – and climate means you can find summer any time of the year. Perth is Australia's western gateway to Europe and Asia, and its geographic position means that Perth is in the most populous time zone in the world.

Perth and surrounds provide unparalleled natural beauty, distinctive venues and hotels, three UNESCO-world heritage sites, unique animals and plants, stunning beaches and islands, excellent food and drink, Aboriginal culture, and a potential opportunity of a lifetime. *See this video of more*.

In due course, we will provide details about registration and dates for the 6-day IWG Meeting and the Pre-Meeting Conference as well as tempt you with some more details about what is in store for you in Perth!

We know Perth is long way for many of you to travel, and we want you to know we are doing our best to keep costs down while showcasing all we have to offer.

From the editor

Irene Renzenbrink

In this first IWG Newsletter for 2024, members who were not present at the Halifax, Nova Scotia meeting from 1st - 6th October 2023 will find information about selected plenary sessions and excursions, thanks to a small team of willing reporters. Thanks to IWG members, **Janet McCord, Jane Skeen** and **Lauren Breen** as well as to Invited Guests, **Sarah Vollman** and **Cristina Felizardo** for their efforts. I am also grateful to **Lori Webster** for allowing us to include a very moving account of her family's experience with the MAID Program in Canada, (Medical Assistance In Dying).

The German magazine interview with **Dr. Joachim Wittkowski,** who died on 23rd October , 2023 recognizes his leadership role in advancing death education and bereavement care throughout Germany and internationally. We were saddened by the news of his death so soon after the meeting .His fellow Halifax Work Group members remember him with affection and acknowledge his valuable contribution to their discussions about "social determinants of health , and structural inequities, diversity with implications for grief experiences."

The Newsletter features heartfelt tributes to our IWG founder, colleague and friend, **Dr. Colin Murray Parkes** who died on 13th January 2024 after a short illness. I am grateful for the reflections that **Maggie Stroebe** and **Debbie Kerslake** have provided for us since attending Colin's funeral on 29th January. Colin's daughter, **Jenny Parkes** has kindly provided some very special family photos. I also wish to thank my friend and colleague, **David Oliviere,** former Head of Education at St Christopher's Hospice, for being such as a caring go-between for all involved in preparing this special section. The information about the scholarship in Colin's name has now taken on a new meaning.

On a personal note, I am deeply grateful for Colin's mentorship and friendship since 1985 when we first met at the London Hospital and then again at the First International Conference on Grief and Bereavement in Contemporary Society in Jerusalem. I remember sitting beside him as we watched, enthralled, as **Sandra Bertman** presented her unique double slide presentation about death, dying and the arts. Colin invited Sandra to offer special presentations before every plenary session at the next

International conference in London in 1988, hosted by Cruse.

Always interested in innovation, Colin was curious about my work as a social worker in a funeral company and visited Australia many times throughout the years. He was also interested in how his Australian colleagues played a part in recovery following natural disasters. I appreciated the depth and breadth of his knowledge but also the quality of his writing, his generosity and humility.

When I watched a You Tube interview that Colin did with **Liz Gleeson** from *Shapes of Grief* in Ireland , Liz told Colin that she saw him as ***‘the David Attenborough of the grief world”.*** He enjoyed that remark very much and smiled broadly.

Irene Renzenbrink

Contributions welcome at: irenz@yahoo.com

(Thanks to Kate Renzenbrink for assistance with formatting and layout)

Erratum: In the September 2023 Newsletter it should’ve stated that Robert (Bob) Fulton’s brother died in bicycle accident, not in a plane crash.

Plenary Session Reports

Halifax IWG Meeting

#GriefKind: Bringing grief literacy to the UK public.

Bianca Neumann, UK

Plenary Presentation,

2 October 2023

Report by Lauren Breen

What a sizzling start to the IWG meeting in Halifax! It was a privilege to hear from **Bianca Neumann,** rising thanatological superstar, and Head of Bereavement at [Sue Ryder](), (Palliative care and bereavement charity) which provides support to people in the United Kingdom through the most difficult times of their lives.

Bianca’s talk was of interest to me for various reasons. I was a member of the IWG work group that theorised and illustrated the concept of grief literacy at the London, Ontario, meeting in 2018, I co-developed the public health model of bereavement care, and have conducted many studies on the facilitators of and barriers to grief support within the context of family, social, and community networks.

Bianca provided a thorough overview of the Grief Kind public education campaign to build grief literacy throughout the UK. Loss and grief are part of life and the purpose of #GriefKind initiatives are to build the community’s capacity to understand grief, support grieving persons, and create grief literate contexts.

Grief Kind initiatives recognise that potential supporters want to help but struggle with their own discomfort about grief and don’t know what to say and do. To help potential supporters find the words and provide care that is likely to be received as supportive, Grief Kind includes practical suggestions about what could be written in a card for a grieving person and other ways to provide support in the wake of loss.

Grief Kind also aims to educate the community via online articles, videos (e.g., “Is there a normal way to grieve?"), and podcast episodes. Additionally, there are Grief Kind spaces, which are weekly, in-person, drop-in sessions. These sessions are led by volunteers and are designed to provide an informal and supportive place where people can come together and share their grief experiences and reduce feelings of loneliness.

Bianca's work is at the forefront of scholarship and was delivered with warmth, humour, and great care. I'm thrilled that the uptake of the Grief Kind initiatives and the feedback received has been so positive. In sum, this was an excellent first plenary that helped to set the scene for the rest of the week.

Panel Discussion: Medical Assistance in Dying (MAID) in Canada- Innovations and Challenges

Plenary Presentation

3 October 2023

Report by Sarah Vollmann

The second plenary session was a compelling and thoughtful offering which was moderated by **Louisa Horne.** The three panellists provided different angles about MAID, which is now legal and available in Canada, after an overview of the program and its eligibility requirements were presented.

Lori Weber shared the story of her husband, who chose to die with MAID due to illness and chronic pain. She stated that MAID actually 'saved her husband's life', providing choice, relief, and agency, as he had reached the threshold of how much pain he could endure. She also described the grief of her experience, and the grief of all family members. Her husband's experience of saying goodbye was reflected upon; he created memory boxes for each of his grandchildren, for example, and met with each one individually before he died. Her family's story was very moving. It is also noteworthy that Lori's husband endured a lengthy and difficult process to gain access to MAID, and that no grief support was offered or provided to family members.

Dr. David Kenneth Wright stated that MAID grief is grief, and expressed the important concern that sometimes, in the highly politicized context of MAID, that grief may be overlooked. He shared several stories of families with a family member who chose MAID; his stories illustrated the complexities of their experiences and testified to their courage and love. He also expressed that with MAID, a person is not dying prematurely, but that they are coming to the journey's end.

Andrea Warnick shared about supporting children when someone they care about is choosing MAID. She had insightful thoughts about helping families to include children and to be honest, and helping adults to take the lead in opening conversations. She also provided age-appropriate language and concepts for discussions with children. She encouraged creating a forum for all questions.

Transcript of Lori Weber's presentation

(published in full with Lori's kind permission)

Rome, 2012

"MAID saved my husband's life. That may sound ironic, or like hyperbole, or like something I am opening my talk with for dramatic effect, but it's not. It is a simple and true statement."

For several years before Ron's death by MAID in July of 2022, his daily life was a struggle. This struggle increased in intensity with each passing month, and without MAID, it is impossible to imagine where that struggle would have taken him. He himself was full of fear for his future because he felt he had reached the threshold of how much pain he could endure, and no drugs other than cannabis and Opioids were giving him relief.

In a blog post for *Dying With Dignity Canada*, Ron described living with this type of pain: "I have been living in a black hole for quite a few years now. This black hole is a place that no one ever wants to visit and, once you end up getting there, getting out again is simply not possible. It's a place no one else can really see into, but which encompasses your whole being and encases you in a special darkness which separates you from the world and the ones you love.

Chronic pain does that, over time, slowly trapping you in your own body and diminishing your basic existence until little is left but the pain and managing the pain, as best you can. I've been living with chronic pain for almost half a century, which is way too long. And so it has come to the point now where the pain must end, and so it will, soon."

Ron had 3 severe chronic illnesses. The main disease was Ankylosing Spondilitis, an auto-immune arthritic disease that causes inflammation and fusion of the spine. He was first diagnosed with it before we met, in his early 20s. Then it seemed to go into remission, or proceed a-typically, but it re-emerged with a vengeance, like a sleeping dragon, when he hit 50. About five years before his death, he was also diagnosed with fibromyalgia, hence more pain. Next, some of the biologics he was prescribed for the AS gave him a terrible case of IBS. As he himself described his situation, "Aside from managing daily severe chronic pain, my ability to walk, eat, sleep, defecate and urinate have all become affected and are frequently very difficult. I have no real quality of life to speak of, and basic life functions are barely manageable."

Ron was able to access MAID because of a change in Bill C-14, the original MAID bill which came into effect in Canada in 2016. At that time, one's death had to be reasonably foreseeable. This limited access to MAID to those with terminal illnesses. While Ron's suffering was immense, his natural death was not foreseeable. He followed the debates on MAID closely, and when Bill C-7 came into effect in March of 2021, he pounced. He hoped he could qualify for the new Track 2 MAID, which was for people's whose natural deaths were not reasonably foreseeable, and who could prove they had done everything possible to find a cure.

The process, however, was anything but smooth, as none of Ron's doctors in Montreal wanted to support his application for MAID. These rejections delayed his provision by at least half a year. We never understood their refusals, and they never explained. Were their objections based on ethics, religion, discomfort, a sense of failure at not having helped him, or fear of reprisals – we never knew.

What we did know was that their lack of support added immensely to Ron's stress and pain levels. He felt that his doctors were impeding his fundamental right to a medically assisted dying assessment, and he found it shocking that none of the doctors he talked to about MAID expressed the slightest amount of compassion or empathy about his situation. In his blog, he wrote, "They seem to have no idea how bad your pain levels have to get, and how much general health deterioration you have to have experienced, before you even want to talk to a doctor about MAID. "

His GP would not support him until he had been seen at a McGill University pain clinic – we called and there was a one-year wait list. Clearly, this doctor did not understand the severity of his pain. For someone like Ron, a year is an eternity. His actual pain doctor, who merely prescribed more drugs, asked him first to read a book called Eat Dirt. We heard another four-letter word ending in t. But we got the book. It basically touted an anti-inflammatory diet that Ron was already more or less following, apart from consuming massive amounts of bone-broth. We tried that too. We bought some, we made some, friends made us some. We were swimming in bone broth – no change.

Eventually, Ron lodged a complaint with our local CIUSSS, a French acronym that basically stands for an integrated university health and social services centre. However, they were without a MAID co-ordinator, and it would be almost 5 months until they hired one, which also delayed the provision. Eventually, in February of 2022, two nurses were sent over to help Ron put in the MAID application, thereby bypassing his doctors. This was followed by the two doctors' visits and assessments in March. Both were palliative care doctors, and they were very sympathetic to Ron's story. They had read his file and had seen how much effort he had put into finding a remedy for his pain. They could see he had tried all three Biologics, NSAIDS, acupuncture, photobiomodulation therapy, all to no effect. His main relief came from cannabis and the many in-house massages he had with the woman we nick-named Saving Grace.

Dorval, Quebec, 2022

After a one-hour interview, the first doctor said he thought Ron definitely qualified for Track 2 MAID. I admit this surprised me, perhaps because of all the doctors' previous refusals, but also because with Track 2 there is a certain amount of subjectivity. Ron had to convince the doctor of his pain and daily suffering, and I wasn't sure he would – he tended to downplay things. The doctor then explained that the required 90-day wait period, which was essential for Track 2 candidates, would start that day.

When he asked how I felt about it all, I could barely speak. It was nice to be asked. As his primary caregiver, my feelings were not often solicited. Caregivers can be overlooked; we learn that our needs come second. We learn that our hardships are not as important as those of the people we are caring for. The fact that this doctor was interested in how all this was affecting me brought me to tears. It's like he had given me permission to pull off the mask. I told him that losing Ron wasn't what I wanted, but that I supported him because I knew how much he was suffering.

The second doctor, who was also very compassionate, came two weeks later and confirmed the diagnosis. This was now real.

As his wife, going through this process was extremely stressful, sad, hopeful, and much of the time, surreal. We had filled out many applications in our 35 years together, but never one to end his life. Telling our 3 daughters and our 3 grandchildren that Ron had chosen to end his life with MAID was very difficult. We did the daughters first – ours together and his two from a previous marriage. They were not entirely surprised, but distraught, nonetheless. We told the three grandchildren a week later, which was brutal. We don't talk enough about death and dying in our culture, especially to children, and we often don't have the words or the comfort level to do so effectively.

Ron impressed me so much that day with the way he explained his decision to them, starting with giving them an overview of the suffering he was experiencing. They knew some of this already. He had stopped being able to do anything with them. He used to take them to movies, to the pool, for lunch, for driving practice. But all that had come to an end about four years earlier. Now, he could barely manage a one-hour visit with them without tiring. He wasn't their funny old grandpa anymore.

Then he clearly explained what MAID was and how it would happen. They were 14, 17 and 20, not little kids, and they understood what he was describing. Many tears flowed that night and I think they left somewhat in shock. The middle boy, who seemed most stoic and dry-eyed at the time, broke down the minute they hit the elevator.

MAID affects every member of the family, profoundly. And, at least in our case, there was zero follow-up support. We had to lean solely on each other, and on what support we could find on our own. The system provided none, although the first doctor did say that he was always available to answer any questions family members might have. My eldest stepdaughter, the kids' mother, resorted to online therapy because she simply could not find a therapist taking new patients post-Covid. No services were offered to us via the CIUSSS.

Sometime in June, Ron chose July 11 for the provision. He had to do it early in July or wait till the end of August when the doctor would be back from vacation. He was eager now. He knew the wait would be difficult for all of us, so the shorter the wait the better. Knowing the exact date of a loved one's death is both a blessing and a curse. It's a blessing because it allows you to prepare and do all the things and say all the things you need to before the person passes. It's a curse because it is exceptionally hard to know that on that precise date your loved one will be gone. The date repeats like a mantra in your mind, to the backdrop of a ticking clock.

For those few months leading up to his provision, we lived in a MAID bubble. All of our thoughts and energy centred on what was to come, and on making Ron's life as full and special as possible up to this day, and on making sure all the words we wanted to speak were spoken. The word "last" took on a new meaning in those months. I wrote an article called "The Last Soup" for Dying with Dignity Canada and they called to ask if Ron and I would be interviewed for their website. Track 2 was still very new, and not many people had accessed it at that point.

The simple act of making soup, a food he could still eat without choking, and which sat well in his messed-up stomach, became invested with extra meaning. So did every episode of the X-files rewatched with his youngest daughter, political debates with the middle one, and visits with his eldest and her three children.

Saying goodbye to those three grandchildren nearly did him in. He had a private visit with each one separately and gave each a memory box he had put together specifically for them. I can't even imagine the toll it took on him to walk them to the door and say that final goodbye. I know that he was completely done in when I found him asleep in his recliner after each one left, the pain etched into his face.

We all understood his desire for MAID and fully supported him. Watching him suffer had been horrible. Watching his body waste away had been hard. Watching his life diminish and lose its lustre had been heart-breaking. We were grateful for this means of ending his suffering, but to this day we are amazed that we were able to face that day, July 11th, with so much stoicism and grace.

A nurse came mid-day to put the ports in Ron's arms while I rubbed his feet. She had difficulty finding a vein; it's like his body was fighting the process. I thought about the word port, the French word for door. It was fitting. She was fitting him with a portal to another world. At 5.30 another nurse arrived to flush the ports and make sure the entry to this other world was clear. Then the doctor arrived at 6pm to offer the provision. Ron's three daughters and I surrounded him on the queen-sized bed, three of us on one side, one at his feet. The doctor and nurse occupied the far side. As required by law, the doctor aske Ron for verbal confirmation that he wanted to proceed. He said yes.

When the doctor asked if we were ready, we all lied and said yes too. How can one ever be ready for a moment like this? But Ron was ready. He nodded and we all told him we loved him. Then he looked around and quipped, I've always wanted four beautiful women in my bed. It lightened the moment and infused the atmosphere with his essence, and his wit. I'm not sure that helped because it reinforced what we would miss.

When the first vial, a tranquilizer, goes in, the person goes way under. We watched Ron's eyes close and a peaceful countenance spread over his face. The others were harder to watch, as their purpose is to stop the person's heart from beating. One daughter could no longer watch, so she left. We had discussed this beforehand, how there would be no shame or judgment if any of us had to leave the room at any time. The rest of us stayed to the end. It took longer than I thought it would. I have no idea how many vials the doctor emptied into the ports, but there were many.

MAID is definitely a family affair and there is not nearly enough support for the family, at least where we were. We only met the nurse-assistant the day of the provision, and the doctor only one time prior, at the assessment. As kind as he was, no relationship was formed, not before and not after. And I get it, he was simply too busy. He was a palliative doctor in two different over-crowded, under-staffed hospitals in Montreal. In an ideal situation though, we would have had more contact.

What helped me get through was support from family and friends, but also from Bridge C-14, an online organization that offers free workshops for those facing MAID, supporting a loved-one facing MAID, or grieving a loss by MAID. My daughters and I attended many of their sessions leading up to Ron's provision, sharing our sorrow and fears, and it was immensely helpful to hear other people share their own. We were suddenly not alone.

Their ten-week grief session changed my life. It started the night after Ron's death. I was raw. But that night I met 4 women from across the country who have become my grief sisters. We have continued to meet weekly, long after the ten weeks were over, and will do so for years to come. I wrote about them in an article published in The Globe and Mail. It opened with the sentence, "I have never met them in person, but I love them all, my grief sisters." Our struggles were the same but different, our responses to the grief varied and identical all at once. The best thing was that we listened to each other's stories without judgment, and checked in with each other through the week. I wrote that the process was like "building houses made of memory, of trauma, but also of love."

When I moved to Dartmouth to be close to my daughter, just months after Ron's death, I felt very alone. I'd had Ron's blessing to come here – he liked the thought that I would be with our daughter. It was my grief sisters who helped me through. I recall one night early on when I looked down on the city from my new 10th floor apartment. I watched the lights twinkle on the houses up the hill, the red tail lights of cars along the highway, and thought how I didn't know a single soul behind any of them, and I felt so alone.

So, I wrote my grief sisters and they wrote back immediately through our chat group. They reminded me I was not alone. They were with me. As I stated in my piece, "They understand the struggle to rebuild, to redefine, to feel solid again. And the lights take on a different hue." We have now shepherded one another through children's weddings, cross-country moves, first birthdays alone, floods, ice-storms, first Christmasses alone, and even a remarriage."

This type of support, specific to MAID, is vital, I believe to recovery. MAID is a very specific type of death – it is an appointment with death. I will never forget when the doctor rang the bell at 6pm, right on time, and I watched him carrying his big black bag. It looked like a crow, sailing down the hall. I knew it contained both relief and dread. I believe my daughters and I all carry a bit of trauma from watching the vials go into the ports that night. There was trauma in watching him die, but there had been trauma in watching him suffer too. But we are recovering slowly. And we are incredibly grateful that Ron was able to find relief from the daily suffering and pain that he endured for as long as he possibly could.

I listened to an interview with Dr. Stephanie Green on the BBC radio one morning, and the interviewer asked her if she was ashamed that Canada had such a high number of deaths by assisted suicide, as the host insisted on calling it. She answered very calmly, and said that she was proud, not ashamed, that we have a humane law that helps people end their suffering. I am paraphrasing, but she said something along those lines, and I was so glad. And then angry. What is there to feel shame about? Ron knew people might oppose MAID so he was guarded in who he told. His colleagues only found out at his memorial. Why should we feel shame that we decide to take control of our own lives and destiny and choose to die when we've had enough suffering.

Bill C-7 is a cautious law, with many built-in safeguards to protect against abuse. I am proud that Ron took advantage of it. I am proud that Canada has this law. If it didn't, I don't like to think where Ron would be now, in some hellish limbo. Actually, he had already decided that he would find a way to end his own life if he hadn't been approved for MAID. I am extremely grateful he didn't need to do that. That would have been far more traumatic for our family. As it was, his death was very peaceful. Hard, but peaceful. And totally legal. I am grateful.

July 11 2022

Lori Weber *is the author of twelve books for young readers, including The Ribbon Leaf, which won the 2023 Canadian Jewish Literary Award. She has also published short fiction, poetry, and non-fiction in several Canadian literary journals. She holds a BA in Creative Writing and English from Concordia University, an MA in English from Acadia University, and a Diploma in Education from McGill.*

A native Montrealer, she lived for several years in Atlantic Canada where she taught English in Nova Scotia and Newfoundland. She taught English at John Abbott College in Quebec for 27 years, before retiring in 2020. Lori currently lives in Dartmouth, Nova Scotia, where she continues to write and talk about her experiences with MAID.

Quotes from Ron's blog, Dying With Dignity Canada, August 2022

https://www.dyingwithdignity.ca/blog/getting-maid-aint-easy/

"I have been living in a black hole for quite a few years now. This black hole is a place that no one ever wants to visit and, once you end up getting there, getting out again is simply not possible. It's a place no one else can really see into, but which encompasses your whole being and encases you in a special darkness which separates you from the world and the ones you love."

"Chronic pain does that, over time, slowly trapping you in your own body and diminishing your basic existence until little is left but the pain and managing the pain, as best you can. I've been living with chronic pain for almost half a century, which is way too long. And so it has come to the point now where the pain must end, and so it will, soon."

"Aside from managing daily severe chronic pain, my ability to walk, eat, sleep, defecate and urinate have all become affected and are frequently very difficult. I have no real quality of life to speak of, and basic life functions are barely manageable."

"The doctors seem to want to impede their patients' fundamental right to a medically-assisted assisted dying assessment. It seemed to me particularly shocking that none of the doctors I talked to about MAID expressed the slightest amount of compassion or empathy about the situation. They seem to have no idea how bad your pain levels have to get, and how much general health deterioration you have to have experienced, before you even want to talk to a doctor about MAID. "

Quotes from (and link)

Finding Empathy Among Grief Sisters

"I have never met them in person, but I love them all, my grief sisters. We are zoom comrades, coming together once a week to laugh, cry, and talk about life after loss."

"They will listen to my story, no judgment, and I to theirs, each of us adding to it week after week, as though we are building houses made of memory, of trauma, but also of love."

Congratulations

Congrats to Dr.Stephen Fleming on receiving the Herman Feifel Award on 6th October 2023 at the Halifax IWG Meeting.

Stephen was presented with his award by Regina Szylit and Ken Doka .

Congrats to Dr Andy Ho,

IWG Board Member Dr Andy Ho, (pictured here with his wife Dr Geri Bun), after receiving the Nanyang Education Award from Nanyang Technological University, Singapore.

IWG MEETING IN HALIFAX:

EXCURSION REPORTS

Visit to the Art Gallery of Nova Scotia- home to the Maud Lewis House and many of her works of art.

Report by Jane Skeen

Our tour guide was Ray Cronin- artist journalist, art curator and former director and CEO of the Art Gallery of Nova Scotia-author of *"Our Maud: the life, art and legacy of Maud Lewis."*

Maud (Dowley) Lewis (Yarmouth, Nova Scotia, 1901-1970) had a progressive debilitating painful disease since early childhood (now presumed to be Juvenile rheumatoid arthritis.- a diagnosis made 25 years after her death) and was physically small and frail. She spent her childhood alone. Encouraged by her mother to paint (using watercolours) and sell Christmas Cards, Maud's career as a folk artist began. She never had any formal art training.

By the age of 36, both Maud's parents had died leaving her penniless and when a failed love affair, illegitimate child, and her living arrangements with extended family proved to be unsustainable, Maud answered an advertisement to be the housekeeper for a local fish peddler Everett Lewis. They married in 1938, for convenience, and lived the rest of their lives in Everett's 12 x 12-foot house in Marshalltown.

The house had no running water or electricity. Maud was unable to do any housework, so started painting kitchen utensils (trays, kettles), then the interior and exterior of the house with her floral designs, then having paintings for sale. Maud's income from her paintings, soon surpassed that of Everett's. The original house has been relocated and restored within the Art Gallery of Nova Scotia.

Throughout Maud's life she always painted using what paint and medium were available (house paint on pieces of timber to donated oil paints on canvas). She adapted her painting style to accommodate her limited movements in her severely disfigured hands.

Oxen Hauling Logs in Winter, c1967

Despite her background, her art is brightly coloured and depicts the normality of her surrounding environment --the landscape, seascapes, animals, and gardens of southwest Nova Scotia. The exhibits on display demonstrate her serial repetition of images and motifs across her career. Her mastery of colour, endless compositional variety and exuberant vernacular style also mark Maud as one of Canada's most formally inventive folk artists.

Three Black Cats, 1955

From her black cats to her cart horses and oxen hauling logs to her quayside scenes of ships in port and Maritime landscape in all seasons. She made paintings that delight in their optimism and vitality. (Ref:agns.ca) Since her death her art has become popular, and some pieces are now selling for high prices.

Stories in Stone: The Old Burying Ground Tour

5 October 2023

Report by Carla Sofka

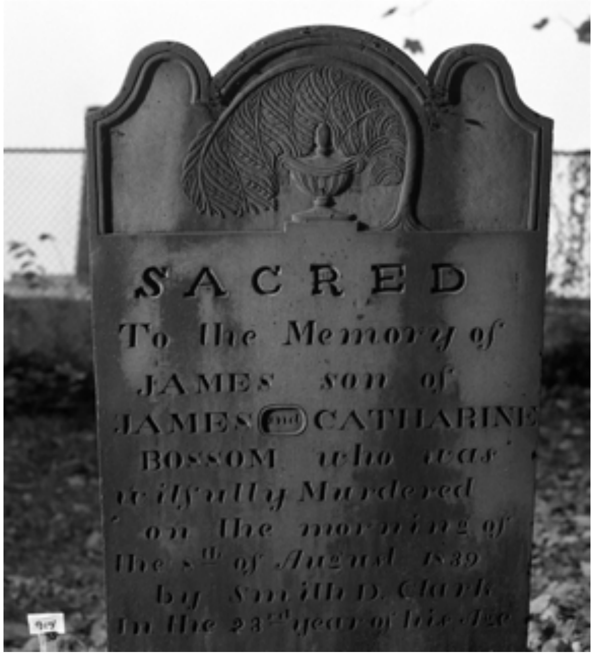
Wednesday afternoon provided perfect weather for a tour of the Old Burying Ground (OBG) in downtown Halifax. Tour guides Vanessa Smith (Nova Scotia Museum Advisor to the OBG Foundation) and Adeena Fox (OBG Foundation Board of Directors) educated us about this historic cemetery, noting that the first grave being dug on June 21, 1749.

Although there are an estimated 10-12,000 burials, approximately 10% have headstones. Women, children, and younger men are more likely to have stones. When a woman died in childbirth, her husband was more likely to be able to afford a stone. Older men may not due to the socioeconomic constraints faced by those who survived them. Abner Stowell's stone was erected by members of his Masonic lodge and has numerous examples of Masonic symbolism.

Some early headstones were imported from Boston and have images that reflect beliefs about death at the time (memento mori = remember you must die) such as winged skulls ("death heads"), an hourglass ("time has run out"), winged angels or cherubs ("soul effigies"), and crossed bones. As time passed, representations of bereavement from the Victorian era became more common (funerary urns, lamps of life extinguished, weeping willows).

Some stones noted the cause of death: synache trachealis (croup); synache maligne (putrid sore throat); yellow fever or falling from the top of the foremast (deaths occurred while on a ship).

James Bossom's stone (below) documents his murder on August 8, 1839, by Smith Clarke but failed to note that Bossom was a bit of a bully who harassed the shop owner and invited him to come out and fight. Although Clarke was sentenced to death, he was granted Royal clemency by Queen Victoria and deported to an unknown location.



While the OBG was closed to burials on August 18, 1844, the Welsford-Parker Monument near the entrance to the cemetery (see photo #3) was erected in memory of Major A.F. Welford and Captain W.B.C.A. Parker, two Halifax men who perished during the Crimean War and was dedicated July 17, 1860.

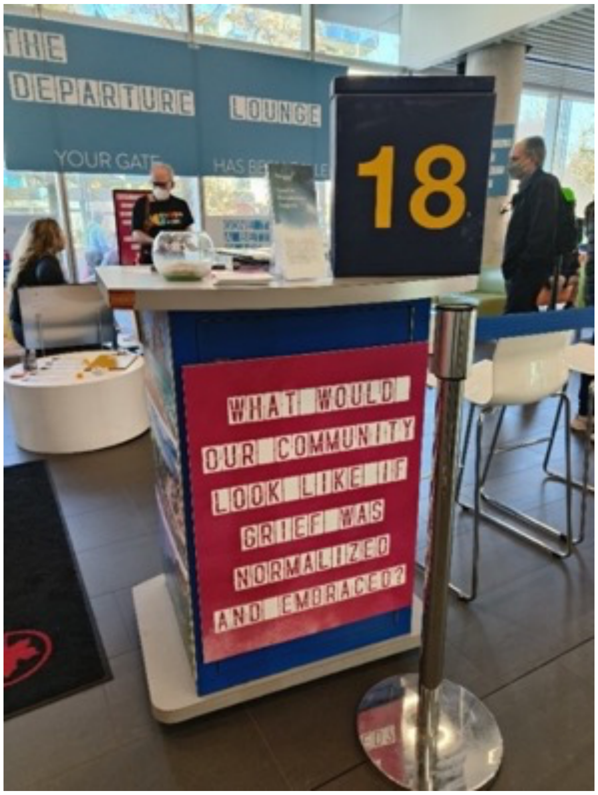
You can find more information on https://oldburyingground.ca/ or @BuryingGround

Halifax Central Library Tour

By Cristina Felizardo, Invited Guest, Portugal

The Halifax Central Library is known for its modern architecture, its collection of books in a variety of genres, and the different spaces it offers its users: reading rooms with comfortable couches and natural light, multimedia rooms with free Internet, rooms for workshops (such as painting, photography, sewing, crafts, etc.), a sound and video editing studio, a music recording studio, and a room dedicated to the First Nations, among others. Five of us accompanied Phil Carverhill downtown on Wednesday afternoon to visit the library.

The Hospice in Halifax had organized a campaign called "The Departure Lounge - Your Gate Has Been Called". The goal of the campaign was to encourage visitors to reflect on death (their own or that of a loved one), dying and bereavement. In this campaign, people were invited to enter the 'airport's' Departures Lounge, Gate 18, with a single and final destination (and a one-way journey): Death. The topic of conversation among the "passengers" was inevitably about dying, death, the finitude of life, human relationships and the emotions that arise.



At the same time, there was an initiative organized as part of Good Grief, Nova Scotia! to raise people's awareness of grief and bereavement, as part of the Grief Literacy Movement, through a booth where we could make personalized pins with the message "Grief is...".

Finally, we were able to visit Susan Cadell's photo exhibit of grief tattoos. Through this exhibit, Susan tells us the stories of love, loss and grief behind each tattoo. They are memorials and true works of art that pay tribute to loved ones and maintain the bonds with those who remain.

Halifax Harbour boat tour

Report by Janet McCord

The boat tour on Wednesday afternoon was a lovely time away in the breezes of Halifax Harbour, a large natural harbour on the Atlantic coast very near to our hotel. Chikako, Fumio, and I walked together to the dock along Lower Water Street, but we could not find our destination. We asked a couple on the street to help us find it, but they were also tourists. Two men who had passed us stopped (when they heard our question), turned around and one said to the other "I'm going to walk them down."

We walked toward the wharf and the one who spoke asked us where we were from, and welcomed us to Halifax. The other man, who seemed to be in a hurry, begged off and continued on his way. The one who walked us told us that the other man was the CEO of the wharf area, and he worked for him.

I found the friendliness and warm welcome to be lovely, although he was a bit amused when I told him we were in Halifax for a conference on dying, death, and grief. He said "well, I guess it's going to happen to all of us!"

There were enough of us that they had to use three boats to accommodate us, equipped with a mast and sails. After boarding, we received a safety demonstration narrated by Jeff Farwell, the Skipper, and his capable assistant Molly – the skippers and assistants on the two other boats were different.

IWG members continued to engage in conversation about matters in their Working Group including Kate Woodthorpe, Sherry Schachter, Kathy Gilbert, and Janet McCord

We learned how to don our life jackets and were told that if we wanted to sit in the front of the boat on the deck, under which was a "floor" of webbing, we must wear those jackets. The Skipper told us about the life raft should there be a need to abandon ship.

The boat had the capacity to sleep 12 (based on two to a bed) and had a lovely galley and sitting area in the cabin. There was seating outside the cabin as well, and many of us huddled to, yes, talk business about our groups. Others were engaged in healthy self-care activities of taking photos, while others were enjoying a glass of beer and the landscape of trees and extraordinarily large houses.

When I interviewed **Kate Woodthorpe** about her experience on the trip, she had this to say: "I loved seeing how the other half live in Halifax (very grandly!) and having the chance to get to know new friends, colleagues, and peers in such a relaxed way. It helped that it was a beautiful autumnal day to be on the water, warm with a fresh breeze and bright blue skies. Thank you for organising it!

A good time was had by all!

Joel Schachter enjoying a beer while gazing at the landscape!

What IWG means to me

IWG Vice-chair, Rana Limbo, PhD, RN, FAAN

Long-time IWG member and former Secretariat, **Dr. Bob Bendiksen,** invited me to attend my first IWG meeting in Hong Kong in 2005. His praise for the organization prepared me for the unique experience I would have, to include workgroups, numerous opportunities for getting acquainted, and potential membership.

Through the meetings I've attended, I realize the value of relationships with IWG members. Some are known internationally for their work in this field; others are lesser known, yet all filled with wisdom and experience in their work with death, dying, and bereavement. Each meeting has provided the opportunity to meet new people, perhaps sitting together at meals or gathering together in a workgroup.

I value the biennial meetings located around the world. I've learned that the meeting format remains the same but the content changes. I learn from the plenary speakers, workgroups, works in progress, and casual conversations. Being introduced to the various cultural practices and experiences adds richness to my life and increases understanding of others.

Finally, I want to summarize the experience of my workgroup in Halifax. The group's membership included a legacy member, a transition member, and several new members and guests. We brought together contemporary ideas (health equity and inclusion, social determinants of health) with models of grief, many proposed by IWG legacy members. All in all, it was a workgroup that made space for differences in a respectful, engaging way and embodied what this organization means to me.

IN MEMORIAM

We bid farewell to

Prof.Dr.phil Joachim Wittkowski

6 November 1945-

24 October 2023

Photo of Joachim Wittkowski
By Daniel Peter, 2019

This is an interview with Joachim published in 2019 inFranken.de, Wurzburg.

Dying is part of life - and yet one's own mortality is a taboo subject for many people.

It is one of the few remaining taboo topics: Why do we so reluctantly talk about death?

A distinction should be made between social and individual taboos. The buzzword taboo is constantly discussed, and the question is whether it is valid on an individual level. How do you know that individuals do not talk about death with those close to them?

I doubt it's a taboo at close range. In social terms this is true. This is because there has been an outsourcing from public life. Both dying and dealing with the dead no longer take place in public spaces. Things used to be different, there was a funeral procession through the whole village. Seen in this way, one can speak of a taboo.

But isn't it difficult to even think about the topic?

What do you think about, the dying process or the loss of life?

About death as the maximum loss of control.

You could say that the loss of life is a kind of maximum insult. Life plays a big role in all of this. People have an attachment to their lives, even if they are not aware of it. This is not meant biologically: they have an inner bond to their life that is, in principle, comparable to the bond to another person. This changes as you move along a timeline: the past is constantly increasing; the future is constantly decreasing. One of the crux of dying is feeling compelled to give up your attachment to your life.

To what extent does it play a role how we personally imagine the afterlife?

Anyone who is of the opinion that earthly life is only a transitory stage and that there is at least one more life or even the actual life afterwards has a completely different relationship before the end of their life. For those who see life as the only opportunity, the loss of life is a much greater catastrophe.

When is the right time to become truly aware of finiteness?

There is an unspoken pedagogical intent behind the question. Tips for correct handling are inappropriate here - because it happens on its own. The young person is in the process of establishing and developing a connection to his life. He sees a lot of future ahead of him and asks himself: What do I do with it? Over time he realizes that he can also lose his life. His idea of existence preoccupies him, but then the whole thing fades into the background again. It's only when you're 60 or 65 that the topic comes up again. Promoted by social markers such as retirement, people become aware that the end appears on the horizon.

How big an impact is it that people are confronted with death over the course of their lives?

The question here is when and how this takes place. These are often so-called normative events. It is said about someone: "You can die at 80." That's okay then. It is different when the order is disturbed. For example, when children and young people die: Children are not allowed to die before their parents - it happens one after the other. In people's minds, a rule is being violated.

Fear of dying, fear of death: what concerns people more?

That depends on age. In early and middle adulthood, thoughts tend to focus more on the loss of one's own life, i.e. death. As people get older, they are more concerned about the side effects of the dying process. An example: Legislation on euthanasia is of particular interest to old people. Because they fear losing their ability to act, i.e. loss of autonomy. They can no longer act the way they want, someone is extending their life, which they no longer want. As a rule, they cope quite well with the fact that their life ends. According to the motto: I had a long life. Some people are fed up with life, even if they are not terminally ill. If you're in your late 80s, you definitely have some kind of impairment, and then many people say, "I've had enough."

Overall, we live longer, and health is not always maintained until the end: Does medical progress bring with it a new longing for death?

People have a sense of when they have exhausted the reservoir of lifetime that is usually allotted to them. Some old people say that they now experience this as an encore. Especially when everyone their age has already died, people feel out of place.

That's just hard to imagine. Keyword: self-preservation instinct as an important driving force for humans. In the end, don't I perhaps think: "It's not enough for me yet"?

There are certainly still vital people in old age. But many people then say, regardless of a medical diagnosis, that they no longer see much point. You're alone, the world is changing in a way that you don't like, you no longer understand a lot of things. There is already a weariness with life. A hallmark of aging is alienation - from yourself and from the world. There are fewer points of contact.

One person is more afraid, one less afraid: why is that?

There is good evidence that there is a general predisposition to fear. The tendency to fear is congenital or acquired in early childhood. Some people react to everything threatening that they encounter in life with strong negative feelings (fear, anger). Exam anxiety, for example, is comparatively harmless. Others face the threats to life more calmly. They're not indifferent to it, but they don't react with such strong fear. That is a fundamental difference. Religiosity can also play a role here, i.e. faith. There can be something very helpful and reassuring about seeing yourself in God's hands. In all situations in life, but especially in this one.

Until then, dying and death seem to be abstract: What does it do to me if death is imminent?

The person in question must adapt to this new reality. Detachment from your own life is an important task that you are not so aware of. In extreme cases, this adjustment can also mean not even noticing the matter. So to repress. But that won't work completely. As a rule, people approach their new reality in tolerable doses, i.e. gradually. This applies to both your own death and that of a close relative. If, for example, the spouse reaches a critical stage and the possibility of losing him or her becomes unforeseeable, then the person is faced with the same situation - we are talking about anticipatory grief here.

People often report that dying people need "a comforting hand" during the process, but often "prefer" to be alone when they take their last breath. Why is that?

It sounds macabre, but you would have to say: “Ask him.” We can only speculate, there is no reasonable evidence for this.

So can we herd animals simply not be alone in the last few hours?

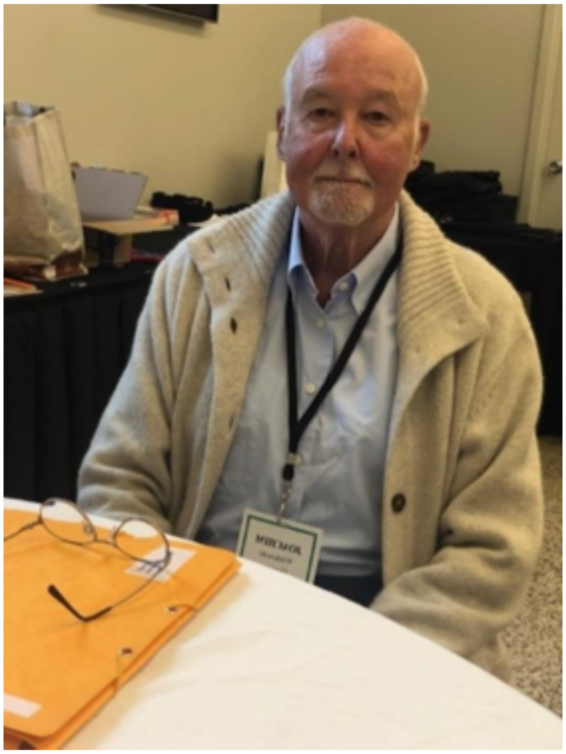
Who says that? It depends on how a person spent his life. There are people who have always been loners. And even those who have a close emotional bond with their partner can be a strong individualist and get along splendidly on their own. Anyone who has lived their life in a self-determined way might now ask: No one has held my hand in my entire life, why should things be different in the last hour?

We often play a role in life that manifests itself over time. Like the strong wife and mother who keeps everything going. Can she at least show herself weak at the end and let herself fall?

The question is whether the role was taken forcibly or did the person consciously move towards it. It's like in life too. You don't become a boss by chance, but because you're made for it. Such a person also wants to be in charge at the very end. Others are generally more grateful to hand over responsibility. For example, the patient-doctor relationship. There are people who trust the doctor completely and leave all decisions to him, and then there are those who are grateful for medical advice and expertise, but want to make the decisions themselves. Why should the end be different than during the long life before?

How much can we actually trust ourselves? For example, with a living will. As a young person, I forgo life-prolonging measures - how can I ensure that I still think the same way if I am directly affected?

A living will should generally be updated from time to time. A decision must be made for those who can no longer express themselves. If you have recently confirmed your order, the argument that you might have changed your mind no longer counts for much. However, my attitude may change if I suddenly become ill. Think ahead: You can only get out of this if you consider eventualities in advance. Certain things are easy to predict and you can think about them for a quiet hour. In the long term, grief can also have positive aspects, such as personal growth.

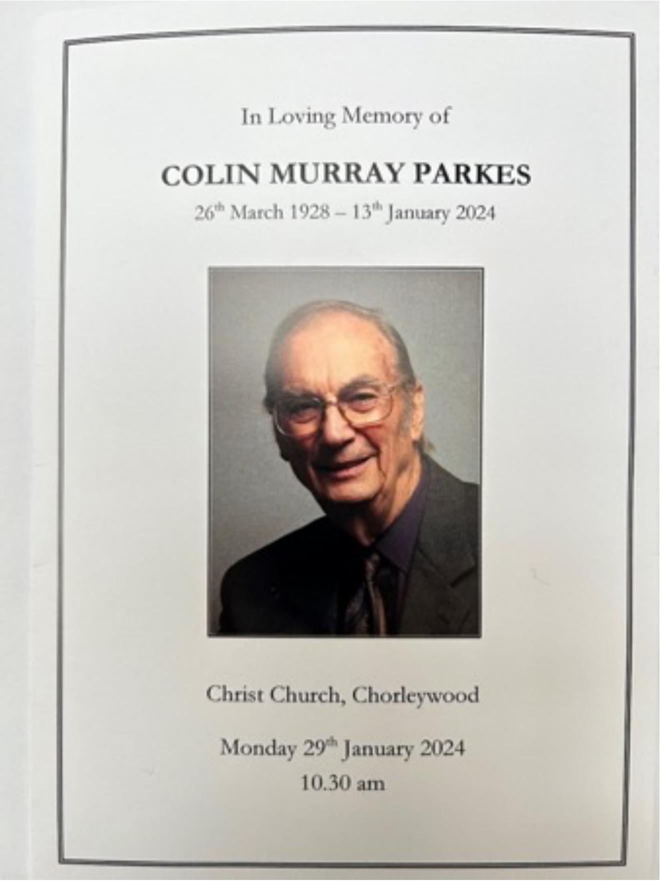


Joachim Wittkowski at the Halifax IWG Meeting, 1-6 October, 2023

Short excursion into grief work: How can "time heal all wounds" when at the time of loss it feels as if the grief will never go away?

I am allergic to the term grief work. Sigmund Freud brought this into the world at the time and it suggests that work is done at some point. But grief never goes away, only its quality changes. Grief is a diverse experience; many people only think of depression. But grief can also have something positive.

On the Death of
Colin Murray Parkes
(1928-2024)



In Loving Memory of

COLIN MURRAY PARKES

26th March 1928 – 13th January 2024

Christ Church, Chorleywood

Monday 29th January 2024
10.30 am

By Margaret Stroebe

The funeral of Colin Murray Parkes took place in the small church at the edge of Chorleywood Common, through which Colin had loved to walk during the years of his long life there.

Approaching the church across these same paths gave the sense of a journey's end. I felt deeply privileged to be able to join family and close friends to celebrate Colin's life and grieve together following his death.

The occasion was strikingly fitting, one full of love and loss, a marvellous commemoration of Colin, personally and professionally. Just as Colin understood grief and grieving, so those nearest to him created a service for him so evidently according to his own values and way of being, with much room for close relationships. Those present comforted each other - reaching out not only to share raw emotions, but also to smile and even laugh together - reflecting Colin's own joy at the beauty of life amidst the sadness of death. And the service throughout was incredibly moving, beautifully thought-through and executed: from the solemn opening onwards, with the coffin borne on the shoulders of Colin's six tall, strong young grandsons.

With the Chiltern Choir, of which Colin and Patricia were founding members, there to sing so beautifully and honour Colin and Patricia in their own special, uplifting way. And with the tributes, which portrayed the very essence of this remarkable man. I so respected the courage of those who spoke – I think it was not easy for any of them to present on this occasion, whether or not they were practised orators.

As Debbie said afterwards: "I'm not usually nervous speaking in public but I was today, it was so important to me to do this right for Colin and his family". In the warm and thankfully not-completely-formal atmosphere surrounding us, encouragement and empathy - with hugs and hands on shoulders to appreciate the speakers and console the family - brought us all closer together. Silent applause was felt loud and clear. Among us was a tiny, very quiet little baby boy, Colin and Patricia's first great grandchild, Will, just ten weeks old. Colin had been well enough to meet him and to hold him and it is not hard to imagine what this meant to him and to his whole family.

Each contributor conveyed their personal sense of who Colin was and what he meant to each of them: as "Dad" to his daughter Jenny, and as "Granddad" to two of his grandsons, Dylan (who spoke words of his mother Caz as well) and Sam. Amazingly, given that professional matters took so much of Colin's time and called him so far away so often, all described him as immensely *present*, demonstrably loving each one of them and being deeply cherished in return, outstandingly good with children, always enjoying their company to the full in his very unique (and occasionally hair-raisingly distracted, inattentive!) way. Colin's cup was always half full, never half empty - despite the burdens of his chosen vocation to assist those traumatized and grief-stricken.

We heard how his sunny disposition shone through his fatherhood: flinging back the curtains of the children's bedrooms in the early morning, to welcome another new day with great gusto. We heard too of his wife Patricia's vital role in supporting him. The words of dedication in his book "Love and Loss" were cited: *"To Patricia Margaret Parkes, the sole object of my romantic attachment and main source of my security"*.

Patricia mentioned to me at the reception "not being part of his work", which I called into question: they were so evidently a team, she *was* an integral, fundamental, unmissable part of his work as well. Just as the tributes showed how much his children and grandchildren were attached to Colin, so was it evident that he too firmly needed them, each contributing to his "secure base", with Patricia at the family centre for him.

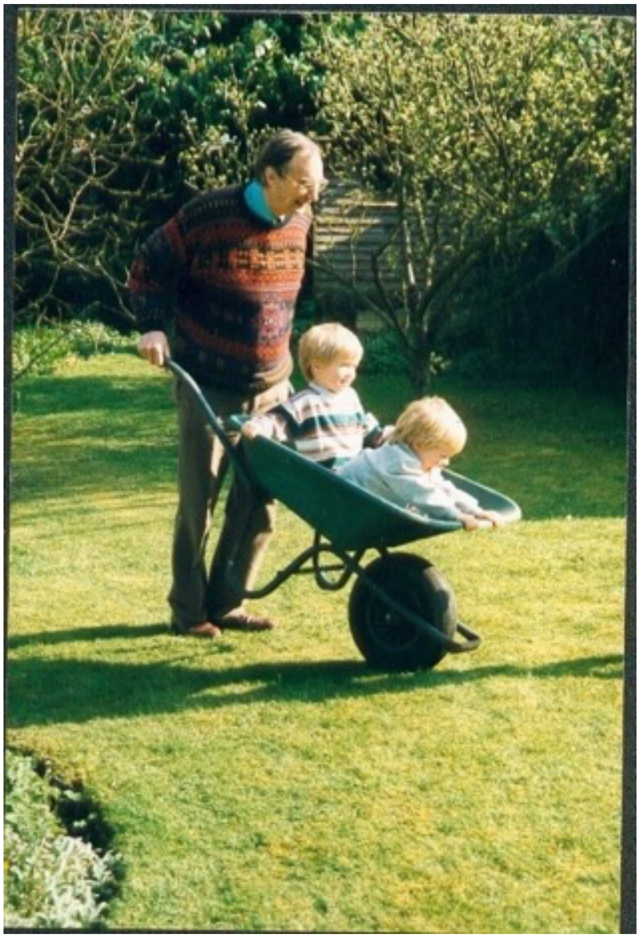
Colin and Patricia on a trip in 2019

Besides being such a devoted family man, Colin cherished his friendships, and one of those closest to him, a long-time neighbour and friend, Ian Watson, shared his treasured memories with us. But first, in this friendship context, and in grateful acknowledgement as well, I would like to mention that his son, Kim Watson, the talented photographer, took the portrait of Colin on the order of service programme copied above. The photograph so touched me. We all have "snaps" of Colin, but this one is way different, somehow managing to convey him in all the intensity, depth and complexity – yet with the lingering sparkle - that we recognize but which is so difficult to capture, be it in pictorial or written mode.

In his speech, Ian described how Colin would always separate his work from his private life, notably at their regular Saturday dinner occasions. Colin rarely mentioned any of his professional activities we were told, except on a few occasions – once when overcome with personal reactions to the terrible tragedy of Aberfan in 1966, in which small schoolchildren and their teachers were killed.

Another time that Colin mentioned his work was far less harrowing but rather typically Colin: perhaps reflecting the balance he sought to maintain by also seeing the joys in life - in this case sprinkled with a touch of impishness. Ian remembered how Colin described teaching young doctors to be sensitive to bereaved people. To this end, he had invited a widow to be interviewed by him during his lecture. As she unfolded her bereavement experience, she recalled how she had met her deceased husband: he had been a lodger at her boarding house for men. As she went on to explain, she had her private toilet with a key, which at some point she shared with this one extra-special lodger. Colin could not resist commenting during his interview with the widow "So it was a marriage of convenience?".

Colin playfully wheeling his grandchildren in the garden, 1998



Tribute was also paid by Debbie Kerslake, former chief executive of Cruse Bereavement Care and herself a major ambassador of bereavement, who represented us - Colin's colleagues - speaking as the close friend that she had soon become to him. Her eloquent words below speak for themselves, illustrating his awesome contributions in so many domains of research and practice. It becomes evident that Colin was a man of great stature in many diverse fields. Any one of these would have served to merit such designations as "giant", "pioneer", "world leader", "the doyen of bereavement research", ones to which the flood of tributes collected since his death attest.

For me professionally, it was the last of these, his unique scientific contributions to the field of bereavement from the 1960's onwards, which has had the most central impact. He was a hugely creative, trail-blazing researcher, and an appealing author and speaker and yes, as was commented among these tributes, I have frequently said that I only had to look at Colin's work to realize that any seemingly-new idea I had, he had come up with before me!

The funeral ceremony drew to a close with a fine and warm reception, at which Colin's daughter Liz so kindly thanked all who had come, and showed us yet another dimension of her Dad's multifaceted life, holding up a battered old hat, relating to his local group of friends who called themselves "Chaps in Hats" and who met regularly in Chorleywood for coffee. More Colin stories and reminiscences were naturally exchanged. One incident that grandson Sam told us about involved Colin's daughter Caz. This never-forgotten "trauma" (what different shapes and forms they come in!) was from her very early childhood.

Here is Colin meeting his four week old great-grandson for the first time on Christmas Day, 2023, the child of the boy in the wheelbarrow

Colin with David Oliviere, former Head of Education at St.Christopher's Hospice

It has remained a sustaining source of smiles since I heard it, sticking in my mind as "The Story of the Wrong Legs". Caz was charging around just as kiddies of toddler age do, coming to a happy halt by clutching the legs of her always-welcoming Dad, only to discover that they were attached to Sir John Bowlby (come to visit), not Dad. Caz was horrified at this discovery and still remembers bawling her head off. No doubt she was lifted high up into the warm arms and comforted by Dad.

It came the time to say a sincere thank you to members of the family privately, as best I could, for sharing Colin with all of us ("Yes, we *did* have to share him with all of you out there" replied one of his daughters with a bright and accepting smile). What could we / would we have done without him, without them to be there for him? The world would have remained a much more desolate place had he not been such a godfather figure to all of us: researchers, practitioners and those themselves bereaved. And then it was time to say goodbye. Leaving the church to take the same path back across Chorleywood Common, the surroundings now seemed rather bleak and lonely, because I had left behind a loving community of family and friends, closely joined through Colin.

There are many abiding reflections. Grief is so full of surprises, even to someone who has been trying to understand it for over four decades. Though we search for patterns as bereavement researchers, one is unprepared. Grieving for Colin is so very different from any other. We knew that he was elderly, we knew that he faced his own death with great dignity, courage and acceptance. Yet this grief is all-consuming. It is hard to turn to other things. There is so much about Colin to think through. And another thing: never has it been so evident to me that one cannot, should not grieve alone.

At the funeral, I was so fortunate to sit next to David Oliviere, former director of education and training at St. Christopher's Hospice. He was very close to Colin, shown in the heart-warming photo below, which I include with David's permission. We grieved together, it was immensely comforting; David too has since described still "reeling" after the funeral, it was so impactful. So I think David and possibly others who attended the service may share my ongoing preoccupation – it is very hard to let go of Colin, and those of us grieving for him try to keep in close contact to ease the sorrow.

In saying goodbye, I think back to my first meeting with Colin, in the early 1980's, when I mentioned my interest in the poetry of grief. With typical generosity, he immediately said he would share his own collection with me, and sure enough, some days later a package arrived through the post, all the way from England to Germany. Given our joint love of literary portrayals, I end with this well-known poetic rendition, words that resonate and comfort a little, following our loss of Colin. They were written by Alfred, Lord Tennyson commemorating the death of his own beloved friend:

I hold it true, whate'er befall;
I feel it, when I sorrow most;
'Tis better to have loved and lost
Than never to have loved at all.

(In Memoriam A. H. H., 27.13-17)

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By Debbie Kerslake

Tribute at Colin's Funeral on behalf of IWG

When I got Jenny's email, asking me to say a few words today, I was hugely honoured, but also if I'm honest, intimidated too! Honoured, because Colin was a pioneer, one of the most important and influential people in the world, in terms of bereavement. Intimidated, because how, in a few minutes, can I pay tribute to this wonderful man, the father-figure in the field of bereavement care, who is so universally loved and revered.

Like so many people, I knew of Colin before I actually met him. Training to be a social worker, I read Colin's *Bereavement; studies of grief in adult life*, and, as someone whose Mum was widowed at the age of 45, I was inspired, thinking this is someone who truly 'gets' bereavement and all the challenges it presents. I also learnt of Colin's huge influence on the hospice sector, working closely with the founder Cicely Saunders, and setting up the first hospice-based bereavement service and carrying out the earliest evaluations of hospice care, beginning a life-long relationship with the Hospice Movement and particularly St. Christopher's.

I was absolutely delighted then when in 1999, I joined Cruse Bereavement Care (Cruse) and was introduced to Colin, as the Life President. Colin was key to Cruse from the beginning, including being Chair for 20 years, introducing supervision and training of volunteers and ensuring practice took into account latest developments in the field. On retiring as Chair, Colin became Cruse's Life President in 1992. I quickly learnt that Colin was very 'hands on' in this role; chairing the Editorial Board of the journal Bereavement Care which he'd set up; sitting on the Board of Trustees; acting as Clinical Advisor; being a media spokesperson; chairing masterclasses; giving presentations and developing Cruse's role in major incidents, drawing on his extensive experience.

Colin helped co-ordinate support to families following the coal spill in Aberfan in 1966, which killed 116 children and 28 adults. In a talk I was at 40 years later, Colin became visibly upset, as he described the personal impact of this involvement. Colin went on to act as adviser in many disasters including, the Bradford Football Club fire, the capsize of the Herald of Free Enterprise, the Pan-American Flight 103 explosion over Lockerbie, the Rwandan genocide and the Indian Ocean earthquake and tsunami. In all these disasters Colin not only focused on those who had been bereaved, but also the support of all the supporters.

Following the 9/11 terrorist attacks, I was in Cruse's Head Office, when a call came in from

Buckingham Palace, seeking advice as to what Queen Elizabeth might say, in her message of condolence to those bereaved. It was Colin, of course, who Cruse turned to. And it is Colin's words - "*Grief is the Price we Pay for Love*" which the Queen used. Now, if you Google the Queen's most famous quotes, this comes up. Prince William, after her Majesty's death, quoted his grandmother using these words. But the words were actually those of Colin.

Shortly after the attacks, Cruse got a call from the Foreign Office asking us to provide support in New York to bereaved UK families who were being flown out. Colin was the first to go, leaving just hours later, and helping establish the systems of support for all the UK families. In Cruse, Colin continued to be key in major incidents, acting as advisor following the 2004 Tsunami, the London bombings and the Grenfell Tower fire.

Colin was always a huge support to me personally, as CEO of Cruse; helping to develop new training; being on call for any difficult client situations; bringing his wisdom and expertise, in his gentle and unassuming way to the Council and presenting at events, from the largest conference to the smallest Branch meeting.

Colin was revered and loved by everyone in Cruse. A volunteer at the Cruse Conference asked if I would take a photo of her, but could I get Colin in the frame. She was too in awe to ask for her photo to be taken with him. I asked on her behalf and of course she got her treasured photo, as well as a lengthy conversation.

When I decided at the age of 60, to retire in 2018, I was embarrassed to tell Colin, because at the age of 90, he was asking me what **more** could he do for Cruse. He was the only person I wanted to be the keynote guest speaker at my final AGM, and of course he was absolutely wonderful.

Colin's impact on Cruse has been immeasurable. Of all the thousands of volunteers, involved with Cruse, over its 65-year history, none has given what Colin has. The longest serving volunteer ever, with a remarkable 60 years of volunteering, he worked tirelessly, always willing to share his experience, his time and his vast expertise.

Colin meeting Queen Elizabeth II at the 60th Anniversary of Cruse Bereavement Care

Colin was a founding member of the International Work Group on Death, Dying and Bereavement (IWG) in 1974. Within minutes of the news of Colin's death being shared to the group, messages started to pour in from all over the world. Individuals shared stories of the support Colin had given in their work as well as in their own bereavements, the inspiration he had provided and the huge admiration they had for him.

As Carl Becker from Japan, simply put it - "He is a loss to our world". I am grateful to Ruth Marijke Smeding, who has put together a short summary of the messages sent in, which I 'd like to share with you:

At IWG, each one of us had her or his own Colin. An inspiring person, a theoretician, a researcher, and clinician, with a sense of humour, curiosity and above all, a "mensch." Recalling him brings images of raucous sessions, at IWG or even on *buses as we travelled to various sites singing all types of songs, ranging from hymns to popular ditties. He brought education, insight, and laughter to all of us. He was a giant in our field with such wonderful inner qualities, like generosity, humour, joyfulness, warmth, playfulness, intelligence, and rigor.*

We at IWG are all grateful to have sung, dined, joked, and worked with him, from London to Japan, Australia, Brazil, Israel, Canada, the US. We would like to mention especially the Working Group on The Cycle of Violence, which produced a still relevant product for today's conflict and wars.

We will cherish his memories and very much miss his warm blanket of collegiality, empowerment of mentorship and sharing of his knowledge. Although death, dying and bereavement is core business, during meetings, Colin could make us smile and happy too. It was work and play.

And when one of us looked at Patricia, just wondering how she was coping with all this presence and liveliness of her husband, a quiet smile was seen on her face.

His spirit and contributions will live on for us all.

It is so appropriate that the IWG had recently launched The Colin Murray Parkes Scholarship.

Like my colleagues from around the world, I am so grateful to have known Colin, for his wisdom, compassion, expertise and support and his generosity in sharing all of these with me and for being my mentor, colleague and friend. He has left me with wonderful memories, including the time when we were both presenting at an event at Stormont, (the Parliament Building of the Northern Ireland Assembly. Colin spotted a beautiful ballroom, which he said was perfect for dancing, and suggested that we sneak in for a waltz, when no-one was looking. On top of all his many qualities, Colin was fun too.

Colin said, *"in every moment of every day of our lives we are permanently changing the world for better or worse. It follows that although the "I" dies, the effect of each life does not. Indeed, viewed that way, we all live on forever. We live on in the consequences of our lives.*

Colin 'got' bereavement and its impact, and he spent a lifetime helping others to 'get' it too. Through Colin's writing, research and practice and his involvement with Cruse Bereavement Support,

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The Colin Murray Parkes Scholarship
(CMP Scholarship)

The Texan Grackle

Background

The idea for this scholarship came from recognizing that Colin Murray Parkes' pioneering research significantly advanced the field of thanatology. In recognition of Colin's contributions and his willingness to foster further research, and in discussions with Colin and one of his daughters, it was agreed to create a named scholarship that would supplement IWG members' research. Colin's enthusiasm resulted in the pledge of a substantial donation to the fund, to be spread over several scholarships over time.

We regret, that with his death, next steps in relation to Colin's commitment will have to be finalized by the current CMP Scholarship Committee (**Danai Papadatou**, **Ruthmarijke Smeding**, and **Betty Davies**) thankfully with the help of one of his daughters. We all remain committed to honouring Colin's legacy in this way and are now soliciting proposals as well as donations from all IWG members.

Scholarship Applications

Scholarship applicants must submit an innovative proposal for their research project aimed at advancing knowledge and leadership in death, dying, or bereavement. The research project is envisioned to be short-term (possibly contributing to a larger project) so that it can be completed between two IWG meetings.

Applications for this round are to be submitted to the CMP Scholarship Committee at info@iwgddb.com by **April 30, 2024.**

The CMP Scholarship Committee comprised of three senior IWG members with extended research experience in the field will select one project from the submitted proposals. The selection will be made within 6 weeks of submission. The announcement of the first CMP Scholar will be announced by **Mid-June 2024**.

The recipient of the scholarship will be required to submit in writing to the IWG membership the outcomes of his/her research project and present the results in person (or via an online connection) at our next meeting in Perth (AUS), times to be scheduled by the local organizing committee.

The CMP Scholarship recipient will be encouraged to add "CMP Parkes Scholar - IWGDDB, 2024-2025" to any publication, after presenting their findings. Caveat: If the CMP Scholar has not been able to finish the project, for whatever reason, this person must return the money s/he received back to the scholarship fund.

Contributions to the Colin Murray Parkes Scholarship Fund

To start the process of contributing to the CMP Scholarship Fund, Ruthmarijke, Danai, and Betty have each pledged $100. We hope that IWG members, and other enthusiasts, will actively help in this way, to sustain Colin's legacy.

IWG Members: Go to the IWG website, login and select Colin M. Parkes Scholarship. Then hit the button "donate" and a drop-down menu allows you to choose the amount of your donation. All amounts are in US Dollars. Fill in your credit card number. Wait for a short while for your receipt to appear.

Former members of the IWG or if any issues accessing the full site: Go to **https://at.grief.org.au/CMP**

As Chuck Corr wrote in his tribute on the list serve, Colin taught all of us and we each have our individual memories of him. He meant so much to each of us who knew him. If you didn't have the opportunity to meet him in person, put his name in Google and enjoy what comes up!

And the bird? This was Colin's favourite bird, the Texan Grackle. When asked why not something more beautiful or showy, Colin answered that he and Patricia had seen many of these during their visits to the US and he loved the unusual sound they made (shared with us by Colin's daughters).

Betty Davies, Danai Papadatou, Ruthmarijke Smeding, (With thanks to Chris Hall for checking payment and data details)

Online article: click the image/article to open in your browser

The Guardian

Psychology

Obituary

Colin Murray Parkes obituary

Psychiatrist whose insights into bereavement were shaped by events such as the Aberfan disaster, the Rwanda genocide and 9/11

Joanna Lyall

Sat 3 Feb 2024 07.07 AEDT

Epitaph

by Merrit Malloy

When I die
Give what's left of me away
To children
And old men that wait to die.
And if you need to cry,
Cry for your brother
Walking the street beside you.
And when you need me,
Put your arms
Around anyone
And give them
What you need to give to me.

I want to leave you something,
Something better
Than words
Or Sounds.

Look for me
In the people I've known
Or loved,
And if you cannot give me away,
At least let me live on your eyes
And not on your mind.

You can love me most
By letting
hands touch hands,
By letting
Bodies touch bodies,
And by letting go
Of children
That need to be free.

Love doesn't die,
People do.
So, when all that's left of me
Is love,
Give me away.

I'll see you at home
In the earth.

Paintings of Halifax, Nova Scotia, Canada by Barbara Thompson