



# The Compassionate Friends of Canada

## When A Child Dies...

## National Newsletter - July/August 2019

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*Transforming the pain of grief into the elixir of hope.*

- Reverend Simon Stephens, Founder, TCF

### On a Mission in Mission, BC

Please join us in welcoming Jennifer and Mike Lago as the new leadership team for the Mission Chapter. They are founding members of the Chapter and will continue the legacy of support initiated by the founder, Richard Lepinsky, in 2014.

Richard and his wife Aline joined the Winnipeg Chapter soon after their teenage son, Nathan, died from viral pneumonia in May 1991. Later, when they moved to Victoria, BC, Richard infused new energy into the position of Chapter Leader and he served a term as President of TCF Canada. When the family moved again, this time to the mainland, Richard lost no time in filling the need for TCF support in his new community of Mission. In Richard's words, "TCF members helped us when we were first bereaved, and helping out is a payback for that help, and the cycle continues."

Richard and Aline will soon be heading for the BC Interior, so don't be surprised if we are soon announcing a new TCF chapter on our BC roster. We've come to think of Richard as our TCF "Johnny Appleseed".

### Donations Appreciated

Some Chapters hold off on meeting during the summer months, while others continue to chug along. We know the treasurers in Avalon, NL, and in Perth, ON, were chugging as we received donations from those two Chapters recently. Thank you.



## ***A note to the Editor...***

Like many volunteer and peer-support organizations, TCF Chapters exchange articles, readings and poems among members to provide support, hope and inspiration. Much of this material is “lovingly lifted” from other publications, and provided that the source is properly acknowledged, and that the copy is not used for commercial gain, this “recycling” has become a generally accepted practice within the TCF community worldwide.

When publishing non-original source material, Chapter newsletter editors should be aware of and comply with the requirements of Canadian intellectual property legislation. As a minimum, this means acknowledging the source of the work. For major articles, it means also obtaining the author’s explicit permission to reprint the work, which may require paying a fee. Note that this approval is necessary each time the work is published. Even if a TCF newsletter receives permission to reproduce copyright material, another cannot simply borrow it, however lovingly. They must obtain their own permission and include appropriate acknowledgement. For detailed information on copyright, please visit [www.cipo.ic.gc.ca](http://www.cipo.ic.gc.ca).

Commercial magazines and newsletters are necessarily less altruistic and frequently impose strict conditions on the copying and distribution of their proprietary material. In particular, US-based publications, such as *Bereavement Magazine / Living with Loss* are likely to take legal steps if their copyright is violated.

Although we are not aware of any specific action, the border may not provide protection from a lawsuit and / or financial penalty that may be filed in the US. Newsletter Editors should be diligent in avoiding exposure to any legal risks by respecting copyright conditions and not publishing material without appropriate permission and / or payment. It would be most regrettable if our best intentions in supporting bereaved parents ended up in an expensive legal battle.



## **20 Years Later...**

It is well known that journaling is a powerful tool to aid in grief recovery and that music can both reflect and trigger powerful emotions. Here is one parent’s story of how they combined to provide creative outlets for his grief after the death of his son.

### **I Just Want You to Come Home**

*“Josh died today. Everything hurts.”*

That was all I could write in my journal, the daily record of my son’s terminal cancer struggle. Twenty years ago, we were given the calm but compassionate statement from our son’s oncologist: “We can no longer defeat this disease.” It was osteogenic sarcoma, the same disease that struck Terry Fox, in the same part of the leg.

Josh was 15, had fought cancer for the previous 16 months, and would live exactly another six months, up to January 13, 2000. We were able to go to London and Paris for a short trip, able to have a great 16<sup>th</sup> birthday, able to do and say things that needed to be said. His courage led us through the terrible six months. I decided to keep a journal of those six months, writing in the morning what was said and done the previous day. But not on January 13. Just those words - "*Everything hurts*" - most accurately describe my link to each one of you.

I ended up writing 110,000 words. Josh suggested I get it published, and I tried, but as a Hollywood agent said (they were briefly interested), "It starts down and continues to go down." But I did get many parts published as essays: *Globe & Mail*, *Toronto Star*, *Reader's Digest*, *Canadian Medical Association Journal*, and an essay in an anthology. I read an essay on the CBC national radio show *This Morning*, and also wrote a two-act play that had six readings and one full performance.

But it took years for the music to come back to me after Josh died. I was asked three times before I started playing guitar in a church band. And then a few years later, it led to a cover band where I played guitar and did back-up vocals. To my surprise, it was a great pleasure, and I knew if Josh was around, he would tease me about it, but wholeheartedly approve. And soon after that, I thought it would be a good experience to record some of the songs the band was doing. Seven years later, after hundreds of performances and 19 recordings, I went out on my own, writing originals. And why write original songs if you can't write about something you care about? The lyrics came first: "*All the faces fading away, the laughter yesterday, and now the hurting, hurting, hurting....*"

I realized there was no point in putting a band together; the songs were deeply personal and gigs would be rare. I was lucky to find the right studio and just called in musicians that were needed for each song. I called in the lead cello player from the Lethbridge Symphony for one song in particular. As soon as he did 30 seconds of warmup, I knew it was the right instrument for that song. And when it was mixed, it became easy to inspire a video tech expert to work with me on the visuals. "*It's a beautiful song, Allan....*" I sometimes hid the tears as we selected the clip, even though at the time it was 18 years since Josh died. In some ways, that song is even more effective than the play or the essays.

Now the song, *I Just Want You To Come Home* (the title came from Toby Boulet, whose son Logan was killed in the Humboldt Broncos bus crash), is on YouTube and all the streaming sites: "*Don't want anyone on this road to feel like this, don't want anyone on this road to be with me....*" People have responded to me on Facebook within minutes of posting. And it has had compliments from people in exactly 50 countries. The strongest reactions come from people who understand loss: bereavement groups, widows, war veterans. Of all the compliments (a few from rock musicians like Alannah Myles), they used the word "beautiful" most often.

Rather than go further into my personal journey over the 20 years—everyone has a deep and hard story to tell—I will bring it down to point-form lessons.

1. If you find something meaningful to do in your child's memory—a project, a scholarship, volunteering, writing, music—it does get better. As I said to another couple, "About an inch a month."
2. You don't get over it; you learn to live with it.
3. Your life is changed forever, and there will be different stresses that come to you.
4. It is almost impossible to "do it alone"; you need support like TCF.

5. If people avoid you, it is because they don't want to see your hurt, or they have their own fears of death. That is their problem, not yours, but it does hurt. It is as if your child never existed. But often you find other people, new friends who are supportive.
6. The most recent statistics prove that the divorce rate for bereaved parents is no different than for the rest of North American society. Your spouse is usually the one who knows the most about your terrible experience, and your bond can often be stronger than you imagined.
7. Favourite topic at TCF meetings: the stupid things people say to you.
8. Try to avoid making major decisions for the first two years. The pain is still raw, but it will settle into a sort of numbness and distraction from numbness.
9. After having a child die, everything else, by comparison, is somewhat easier.
10. Prescriptions and addictions can make the pain go away temporarily, but it is always there and needs to be faced, like an elephant under the carpet.
11. "Wounded" is a word that many bereaved parents understand. The wound never heals properly, but time and distractions will cover it so others don't see it.
12. If by some miracle or magic, I was told before we were going to have a child that our son would have 14 years of wonder and happiness, and 22 months with cancer, misery, pain and death, I would still choose to have my son. My wife and I still love him, still think of him, still laugh at his jokes, still wonder at his courage facing death. Yes, I would do it again.

*Allan Wilson lives in Lethbridge, AB, with his wife Sandy, where they lead their local TCF Chapter.*

### **Bright idea:**



Once a Chapter is established and ticking along, the steering committee will be ready to reach out to spread awareness of TCF and the local Chapter. The Perth, ON, Chapter, now two years out, sent in this suggestion:

Many jurisdictions encourage groups to adopt a section of road or highway, to keep it free of litter, and in recognition of the volunteer service, they will post a sign saying something along the lines of "Highway XX has been adopted by The Compassionate Friends of XYZ". The Perth Chapter has already cleaned up one stretch of a local roadway, and now they are working on picking up along a section of a county road, which will make them eligible to have a sign posted to recognize their chapter.

The jurisdictions (counties, townships, cities, regional districts, etc.) will vary by location, and so will the application process, but the idea itself could be applicable to a majority of our chapters.

Well done, TCF Perth, ON, and thank you for passing this along.