

Reflections by Paul Dawson - NCPDG Board President

Losing a spouse to Parkinson's is an overwhelming, emotional, extremely difficult experience. It is a mixture of great sadness at the loss and joy for the blessings we've enjoyed along the way. One of the ways I am coping is to share my thoughts, and more specifically my appreciation for those who have had a positive impact on us. Although it may be presumptuous, if that's the right word, for me to use this forum to communicate how I feel, I hope it speaks to you on some level. I hope it points you towards resources perhaps you weren't aware of, and how we together can make that Parkinson's journey a very positive one.

Remembering a Life Well-Lived: *Eva Dawson* March 1945 - June 2018

Eva heard the diagnosis of Parkinson's more than twenty-one years ago, at last putting a label on the problems she had been experiencing for years. Now she has reached the end of her journey in this life. With your permission I'd like to reflect on many of the gifts we've received.



PD itself is certainly NOT a gift. Parkinson's is a cruel, relentless disease. Not to diminish the many other maladies that could befall us, like Alzheimer's, vicious cancers, debilitating heart disease, stroke, and others, Parkinson's has its own insidious impact on patients, caregivers and their families.

"A *progressive neurological disease*" means for some, more than two decades of fairly stable symptoms, then a jarring speedbump, and a decline. In response to that we develop new ways of coping, feeling that we've reached "the new normal."

But like a thrill ride at an amusement park, suddenly there's *another* speedbump... or two... followed by an even steeper decline. We develop a cautious perspective that this is "*the new, new normal*", with a confidence level shakier than the last time. Intellectually we know that none of us has that "E" coupon "*all-rides-forever*" pass. Still, we continue to hope, to expect, that we'll be around a while longer. With her final hospitalization and decline, initiated in Eva's case by an inability to swallow, it became clear that hospice and palliative care at home was our best path.

Eva and I had tremendous help all along the journey. I'd like to acknowledge that. So many individuals and groups had a wonderfully powerful impact, making life much richer. Challenges were better anticipated and therefore easier to deal with. And we had a sense – no, a knowledge – that we were not in it alone. But Parkinson's remains a truly relentless disease.

There's a fear when giving recognition for many such gifts that someone or some group that had significant impact might inadvertently be left out. But we forge ahead, trusting that if you've touched us you have felt our gratitude, whether acknowledged here or not.

From early on, many friends and family members on learning she had Parkinson's offered what support they could. Our faith in God and our church family was always present, always giving, from the simple gesture of bringing a stool for Eva to sit on when singing in church with the "*New Creation Singers*", to accommodating her need for rest during the work day when she was the church's administrator. Friends with whom she worshiped, studied, shared joys and concerns, and, yes, partied – Oh how Eva loved to party! – were a constant source of joy and comfort.

But many more positive folks helped along the way. Who would have thought that a young TV comedy actor would have contributed so much to our Parkinson's community by being very public and proactive about his (our) disease. Michael J. Fox's substantial contribution towards

funding and setting standards for meaningful Parkinson's research is far exceeded by his lifting the stigma previously felt by so many dealing with the disease.

Leaders in the Parkinson's community, like David Higgins, who serves on the MJFF *Public Policy Council* and is the Parkinson's patient representative on *California Integrative Regenerative Medicine (CIRM)* board, bring a personal perspective and informed advocacy to steer research in the most productive directions, and hold researchers responsible for top quality work and for sharing their discoveries.

Parkinson's Association San Diego has offered us services – seminars, equipment exchange, and support for local SGs. Enthusiastic support over the years for individuals and groups serving the Parkinson's community has been received from current Executive Director Chris Buscher and from previous EDs including Jerry Henberger.

Tremble Clefs brought us the joy of singing, improved speech, breathing and swallowing, and a ton of fun. Karen Hesley, creator and the organizational leader of TCs, along with several north county directors and accompanists over the years, led us in exciting and renewing retreats that joined *Tremble Clef* groups from around the country in Palm Springs, and later in Phoenix. We enjoyed singing together at rehearsals, entertaining in the community for seniors, retirement homes, and even sharing singing with a wonderful high school choir.

County-wide support group leadership including Nancy Floodberg, Point Loma, and David Higgins, Mission Valley and UCSD groups, helped us enrich our own local programs and experiences.

Good times shared with so many friends – Thelma, making her pool available for swimming exercise and her home for gatherings. Madonna, always the gracious hostess, welcoming us to group gatherings or to stuff Newsletter envelopes, and ready with a fresh baked goodie.

Parkinson's exercise classes at *Tri City Medical Center* under Tracy Park, dance classes with Cheryl McIlhan, and several annual Parkinson's walks with PASD all contributed to Eva's strength, balance and endurance - and mental agility too.

NCPSPG Support Group meetings included inspiring speakers and breakout groups so vital for discussing challenges and sharing ways of coping. Rex and Irene providing leadership for their communities, Madonna and the leadership team keeping Oceanside rolling along. The NCPSPG Board of Directors dealing with administrative details and cultivating a vision for our future.

Small social gatherings in private homes where we could talk about anything – and no fear of making someone uncomfortable if a drink is spilled, or medication wears off. Mary Jo and Dick, Sam and Ruth, Rex and Ann, Brigit and Ken, Madonna and granddaughters, and so many others for hosting small groups. Thanks Sam for bringing the concept to fruition.

Picnics and Holiday Luncheons where many old friends share memories and new friends connect...Wow! We've benefitted from so many activities and events.

And particularly all the friends we've made, who share the journey – sharing concerns and perspectives, sharing support and love, sharing the joy of knowing one another. The journey has been far richer because of you all.



Eva continues her journey through donation of her body to UCSD School of Medicine, hoping to help advance the great Parkinson's research happening there.

I intend to continue my involvement in NCPSPG. It's the most meaningful action I can take to fight Parkinson's, and to fight for those traveling the same path.

Thank you for sharing the journey and allowing me to share my thoughts. - Paul Dawson