

From Henry's Desk *by Henry Holland*
The Grief of Post-Polio Syndrome

I went to another funeral this month. Another long time member of our Post-Polio Support Group died. His name was Mel Bleiweiss. Like many of us Mel was courageous, persevering, gentle, generous and a man of integrity. Each month I read a lot of Post-Polio Support Group newsletters from around the country. The mention of the deaths of polio survivors is becoming more frequent. The vast majority of our number originated from thousands of people who had polio in the twenty-year span from 1935 to 1955. Thus, most of us are over fifty years old and many of us are over sixty years old. Most polio surveys indicate that the average age of polio survivors with Post-Polio Syndrome (PPS) is around sixty-two to sixty-four years. Thus, we are entering an age group where death becomes an increasingly higher risk.

I looked at the obituaries in today's Richmond Times Dispatch (May 9, 2004) and found twenty-five deaths in which the age of death was mentioned. Of the fourteen women who died, ten were over the age of eighty. Of the eleven men listed, six were over the age of seventy. These numbers are somewhat indicative of national averages. The average death age for women in the USA is approaching 80 (around 78). The average death age for men is around 74 to 75. Are polio survivors at a greater risk to succumb before reaching an average life span? The answer to that question is not clear, but gives one reason to think.

So much of what happens as the result of PPS may increase the risk of some life threatening event. Because of increased stress on the total body system, reduced activity, weight gain, systolic and/or diastolic hypertension, accidents/falls, infections, emotional factors and aging before our time, PPSers very well may be at a higher risk to die at an earlier age than our relatively able bodied peers. I wrote an article on "Is PPS Fatal" two years ago and came to the conclusion that PPS is not likely to be fatal. The reader can read that article on our web page at <http://www.cvppsg.org/index2.html>. Look at the link for "From Henry's Desk" and the article is listed.

I recently went to a medical conference on stroke. The five risk factors given for increasing one's likelihood of having a stroke or a cardiovascular event were cited as:

1. Elevated glucose (blood sugar) even at moderate levels
2. Elevated systolic or diastolic blood pressure. The optimal blood pressure is 130/80 or below.
3. Elevated cholesterol or blood lipids. The statin drugs are effective in lowering cholesterol, especially the bad cholesterol or LDL
4. A history of tobacco or illegal drug use
5. Lack of exercise.

With all of these medical warnings I believe that we still have to deal with the grief of PPS, which alone can be a burden. Grief is often caused by the loss of a loved one or the loss of a significant part of one's identity. The vast majority of polio survivors had an identity apart from polio. This identity may have been associated with marriage, parenting, occupation or career, community involvement or by religion. With PPS, all of the previously mentioned components of our identities may have been affected and lost

in part. We are confronted with “Why is this happening to me now?” We are having to make life style changes that we did not expect and the necessities of these changes does not seem fair after so many successful adjustments earlier in life.

As a result of PPS our independence may be lost or at least threatened. Many of us have to depend more on our spouse, family members and friends. Some of us have to pay for necessary help. Some of us are no longer able to work and have to live on fixed incomes with rising medical costs. Some of us are not able to drive a motor vehicle as safely as in the past. Some of us have been forced prematurely to bring a successful career to a close. Some of us can no longer safely lift our grandchildren. Physical barriers can often be overcome or marginalized. Every older person eventually faces a reduction of activity and energy, but PPSers often face these reductions long before becoming truly elderly.

All of these realities for many polio survivors produce a feeling of grief which may never be fully resolved. I think many of us have worked through this grief. Hopefully we will not withdraw or isolate ourselves from family members, friends and other polio survivors. Expressing and talking about what we feel is usually helpful and therapeutic. Often the inner resources of one's faith can certainly be both helpful and inspiring in facing the grief of PPS. I have also found that some of the poetry that I read and studied in my youth can be uplifting and even more meaningful as I grow older. One example is the poetry of English poet William Blake (1757 - 1827). The excerpt below, written in 1808, reminds us “not to cease from mental fight.” Most PPSers can understand this approach to the grief of PPS.

And did those feet in ancient time
Walk upon England's mountains green?
And was the holy Lamb of God
On England's pleasant pastures seen?

And did the Countenance Divine
Shine forth upon our clouded hills?
And was Jerusalem builded here
Among these dark Satanic mills?

Bring me my bow of burning gold:
Bring me my arrows of desire:
Bring me my spear: O clouds unfold!
Bring me my chariot of fire.

I will not cease from mental fight,
Nor shall my sword sleep in my hand
Till we have built Jerusalem
In England's green and pleasant land.