



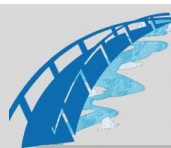
ISSUES OF AGING IN PEOPLE WITH PWS

Among the issues of aging affecting everyone, the people with PWS need support in dealing with:

- 1. Changing friendships as people move**
 - a. People move**
 - b. Friendships disconnect**
 - c. As people age, friends develop emotional issues affecting friendships**
 - d. People die**

How do people deal with these changes affecting more people as they age? All these social changes cause grieving.

- 2. Changing places of employment**
 - a. As people age, functioning can change, requiring changes in types and places of employment**
 - b. At a certain age and level of functioning, it may become important to cease working**
 - c. Physical functioning declines with age and therefore ability to function on a job that was handled well earlier is now beyond the older person's ability**
- 3. Losing significant others, as people die (especially parents, grandparents, siblings, etc.)**
 - a. In the past there was a tendency to "protect" the person with special needs and not involve them in funerals and other mourning rituals. This "protection" left them with significant emotional issues since the stages of mourning were never processed**
 - b. Therefore, encouraging the person with PWS to be a full participant in all mourning rituals is very important. Of course, there is always a need for support. Sometimes, the person with PWS may express feelings with great emotion and others may not seem to express feelings at all in the beginning**
 - c. In our group home, many years ago we had a large group of residents who had lost a parent, sibling, or grandparent. However, the over-protection by the parents prevented their participation in the entire grieving rituals. Our psychiatrist during this time suggested we do a Bereavement Group. We met once every 2 weeks**



for 2 years. We had the residents write good-bye letters to the person who died, we had them bring pictures, we had them share feelings with the group, and we had them go visit the burial site with a relative or a staff person. Most of all they processed their feelings.

- d. **Preparing people when a close relative is terminal. We had a resident whose father was terminal. He knew that his father was very ill, but no one would share with him the grim news. Once, on a Friday afternoon, one of his brothers came to visit along with his wife, who was a doctor. I asked her if she could explain to our resident the father's situation. She explained simply but clearly the medical status. Then, we agreed that the family would update me and I would share with him on a daily basis. Also, we were adamant that he would participate in the entire grieving process. When the father passed away, I was notified. I came to the group home, he looked at me and said, "It happened, right?" I said yes. Pack a bag, you are being picked up and will go home for the week.**
- e. **In our experience ever since then, the person with PWS needs to be an integral part of the bereavement process. His need to process the loss and go through the stages of grief are as important as for anyone else**

4. Cognitive issues

- a. **While there is no concrete evidence of early cognitive decline or dementia, there is a need for screening**
- b. **Screening should be done from age 40**
- c. **Then, when any signs of early aging appear, preventative measures can be taken**
- d. **Tools of evaluation:**
 - i. **Short Portable Mental Status Questionnaire (SPMSQ)**
 - ii. **Montreal Cognitive Assessment (MOCA)**
 - iii. **There are other evaluation tools**
- e. **When there is a change in mental status**
 - i. **Testing and retesting**
 - ii. **Psychotherapeutic consult**
 - iii. **Psychiatric consult**
 - iv. **Neurological consult**
- f. **Other treatable causes of memory problems**

