

GRIEF AND PRADER-WILLI SYNDROME

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As our children are living longer, we need to address new issues. At the national office, due to our bereavement program, we get calls on a variety of deaths – often where the issue is supporting the child/adult with Prader-Willi syndrome who is dealing with a loss of a parent, sibling, or roommate. I have been doing bereavement groups for 18 years. The following are suggestions that may help in understanding the grief process of a person with the syndrome and how to provide support.

POSSIBLE GRIEF REACTIONS FROM A CHILD OR ADULT WITH PWS

- A lot of questions that may be hard to answer!
- Anger – lashing out
- Refusal to talk about it – isolation
- Self abuse accentuating
- Fear of losing others
- Guilt – logical and illogical
- Fear of own death -- health phobias
- A surprising external lack of response/emotion
- Setbacks in behavior after a home visit
- Occasional setbacks for unknown reasons

REMEMBER – PEOPLE WITH PWS OFTEN

- Lead more protected lives – have less exposure to dealing with “real world” issues.
- Think more concretely rather than abstractly and thus may have a harder time with the dimensions of death, e.g. that it is irreversible and that everyone dies.
- See the world from an egocentric viewpoint – how it affects them. They also may blame themselves for the death.
- Have a limited ability to communicate feelings.
- Often have a lot of loss and grief issues to deal with – loss of staff or roommates through moves; dealing with rejection from others; grieving over all of the restrictions on their life; not being able to have children, drive, marry, etc. – yet bright enough to know what they are missing.

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HOW TO PROVIDE SUPPORT

- Do acknowledge the death and ongoing loss issues.
- Do ask questions and *listen* to the answer.
- Do look at developmental not chronological age. For example, a child before the age of eight may think a person is only dead for a period of time and will come back.
- Do understand that acting out may be due to grief issues.
- Do acknowledge special occasions and help the person with PWS find a way to keep the memory of their loved one alive (e.g. view pictures or videos together, light a special candle on the deceased person's birthday, buy an angel for the tree in memory of their loved one.)
- Do expect the person with PWS to become somewhat phobic and have concerns that may seem illogical to you but are very real to him/her.
- Do use simple and direct language about death.
- Do all you can to help the family with getting the person with PWS to the funeral. If in placement, staff support for that person at the funeral would be optimum.
- Do be alert to the potential of depression and psychosis.
- Do be careful if you are using religion as a support, to keep it within the person and their family's own belief system. Ask the person with PWS what *they* think happens after death.
- Don't get caught up in "stages of grief." They are only windows to look into the human experience rather than an exact prescription of how a person should grieve. Grief is a roller coaster rather than a ladder. There is no "right" or "wrong" way to grieve.

For more information about Prader-Willi syndrome please contact Prader-Willi California Foundation toll-free within California at 800.400.9994 or outside California at 310.372.5053 or visit our website at www.PWCF.org. The national Prader-Willi Syndrome Association may be reached at 800-926-4797 or www.pwsausa.org.

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