Healing, Hope, and Acceptance

Grief can occur with any loss and grieving is a necessary step in the healing process.

Grief is the response to loss, particularly to the loss of someone or something that has died, to which a bond or affection was formed. Grieving the loss of life is what most people think of when we talk about grief. In fact, the definition of grief is deep sorrow, especially that caused by someone's death. However, it is also important to acknowledge anticipatory grief and disenfranchised grief.

You do not have to go through the grieving process alone. There is help and support within the PWS community.

Anticipatory grief is grief that occurs when a loved one is severely ill or in the process of dying. This type of grief is common when you see a change or deterioration of a loved one, and we begin to mourn that loss.

Disenfranchised grief is grief experienced when a loss occurs that is not openly acknowledged, publicly mourned, or socially supported. Any loss that one experiences that is not commonly experienced by others can lead to disenfranchised grief. Disenfranchised grief can be experienced when:

- Parents receive the information that their child has been diagnosed with Prader-Willi syndrome.
- Individuals with the syndrome realize some of the limitations they face because of the syndrome; not living independently or not getting a driver's license.
- A child or adult with PWS moves out of the family home into a group home or supported living situation.

PWSA | USA offers grief support to individuals diagnosed with PWS and to parents, family members, and caregivers of those diagnosed with PWS who may be dealing with any type of grief. Call us at (941) 312-0400 or email info@pwsausa.org.

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