



## Prader-Willi Syndrome: Growing Older by Terrance James, PhD

A Review by Barb Dorn (USA)

*Prader-Willi Syndrome: Growing Older* by Terrance James, PhD is an enlightening book that begins to explore a topic that is becoming very pertinent - our aging population of adults with PWS. James interviewed parents, caregivers and 14 adults with PWS ages 40+ years who reside in Western Canada. He covers a variety of topics that impact these aging adults including services, genetics, health, residential supports, and employment as well as their aging parents and/or caregivers. He also focuses on quality of life issues and shares the personal views and experiences of these adults.

The first few chapters are very informative and help readers gain a historical perspective on the changes and advances in the field of developmental disabilities and Prader-Willi syndrome. “Younger” readers will learn to appreciate the advances in genetics and diagnosis of PWS. (Most adults 40+ years old did not and many do not have genetic confirmation of the diagnosis). James briefly touches upon the many areas impacted by the aging process (cognition, behavior, physical health, mental health – just to name a few). He shares research resources from all over the world that supports his findings.

James also devotes one chapter to the topic of aging parents – an emotional topic near and dear to all parents of adults with PWS. He touches on several concerns about the future including family, residential and funding concerns of government programs. Even though most references are for Canadian programs, it was interesting to learn that we share many of the same challenges and concerns.

My favorite part of the book includes the chapters that share the personal life experiences of 14 older adults. They share their accomplishments and what things have helped to improve their quality of life. It is enlightening to read about the various models of residential support these adults are utilizing. It is also great to see how many of them are taking advantage of volunteer opportunities out in their community to keep them connected to social and cognitive stimulation when employment was no longer a full time option. As the parent of a young adult with PWS, these profiles forced me to take a personal look at my son’s current life and reflect on his personal needs and dreams.

*Prader-Willi Syndrome: Growing Older* is a quick, enjoyable resource on a topic that needs more research, discussion and attention. Even though the book focuses on aging adults with PWS residing in Canada, the topics, issues and concerns cross national boundaries. It begins an initiative in starting to share more on this much needed topic of aging with PWS.