



Usher syndrome: About Us, by Us

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COLLECTION EDITED BY Damian Mellifont

COLLECTION
Disability Studies

EDITION
1st edition

MARKET
College/higher education
and Professional and
scholarly

This course reading...

- A unique resource written by and for individuals with Usher syndrome and their communities.
- Covers life stages, from childhood to aging, with practical insights on communication and wellness.
- Combines lived experiences with lived expert knowledge to bridge gaps in health and social care.
- Ideal for professionals and students in disability studies, health and social care.

What is Usher syndrome and how does it shape life experiences, and what strategies can enhance communication and well-being?

Usher Syndrome: About Us, by Us, is a comprehensive resource created by those with lived experience, lived knowledge and lived expertise of Usher syndrome. It explores the syndrome's prevalence, types, and the challenges of parenting, learning, working, and aging with Usher syndrome. The book also covers essential communication strategies and wellness practices. Designed for health and social care students, professionals, practitioners and policymakers, it highlights the lived experiences and needs of individuals with Usher syndrome, ensuring a better understanding among social contacts, colleagues, and support workers.

Ideal for professionals and students in disability studies, health and social care, educators, policymakers, and families seeking deeper insights into living with Usher syndrome.

Annmaree Watharow, a Lived Experience Research Fellow at the University of Sydney, explores Usher syndrome's impact in her life, family and work. She is the author of two books on dual sensory impairment. **Emily Shepard** is the parent of a teen with Usher syndrome, as well as co-founder and CEO of UsherKids Australia, a support organisation for families of children and young people with Usher syndrome. Emily is also the clinic manager at the Melbourne Collaborative Sensory Clinic, a multidisciplinary clinic at the University of Melbourne providing streamlined, collaborative care for those with Usher syndrome. **Emma Boswell** who herself has Usher is the National Manager of Usher Services at a UK charity, she is also the Chair of the Usher Network under Deafblind International. She advocates for and improves support for people with Usher syndrome.

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