



Library Catalogue (Oct 2019)

Publication	Description
Batten Disease: An Easy to Understand Guide	This book is written in layman's language and covers Batten Disease, what it is, how it is diagnosed, how it is inherited, how it affects an individual, and about BDSRA. (L W Johnston, et. Al.)
Coping for Care providers	This book looks at the effects of Batten Disease on the family and how it can wear down the primary careproviders, i.e. Mum and Dad, and the importance of developing good coping skills. (Elise E. Labbe, Ph.D.)
Teach and Be taught; A Guide to Teaching Students with Batten Disease	A practical information book for parents and teachers that addresses the issues of having a child with Batten Disease in school. Includes sections on Individualised Education Program (IEP), alternative communication, vision, social interactions, therapy, law, etc. (Wendy Bills, M.Ed., et. Al.)
Therapy and Teaching with Batten Disease	A data source based on survey research with Australian participants. Investigates similarities of care, strategies used by parents, teachers and therapists. (Compiled by BDSRA Australian Chapter)
Batten Disease and Schooling in Australia	A support resource for teachers and parents: Entering the school system and information for Educators, Parents & School Administrators. (Kelvin Shem (B.Ed) & BDSRA Australian Chapter)
Will You Walk with Us? – Batten Disease and Hospice Care	A book that is designed for Hospice workers to quickly give them an understanding of Batten Disease and what is happening including end stages, its effect on the family and that the parents are professionals. (L W Johnston, et. Al.)

Publication	Description
Fundraising Ideas for Working Toward a Cure	A simple book that presents several ideas for fund-raising events. It is designed that when someone selects a fundraising event, someone from the BDSRA who has had a success with that event will help with the practical side of it and act as a guide. (L Houghtby & S Killebrew-Ross)
Handy Helpful Hints for Careproviders	A compilation of ideas from parents and other care providers for caring for a child/ren with Batten Disease. (Robert Wilhelm, et. Al.)
Batten Disease; Insights for Parents	This book is a companion to "Batten Disease; An Easy to Understand Guide." It is for parents of children with Batten Disease and deals with the questions and issues that parents want to know. (L W Johnston, et. Al.)
Gastrointestinal System	About the Gastrointestinal system, how it works from the lips through the end, how it is affected by Batten Disease. Chapters on nutrition, feeding techniques, feeding devices and problem solving. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
Pressure Sores	What is a pressure sore, causes, how to prevent and how to treat. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
Dental Issues & Mouth Care	What to look for, causes and suggested procedures. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
Physical Therapy	What is appropriate, causes and suggested practices. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
How to Organise Special Events & Festivals	A Practical guide for Non-Profit Clubs & Associations. (Rob Tonge, Tourism Management Series)
Instructions for Hospitals and Emergency Room Visits	Instructions for Hospitals and Emergency Room Visits. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)

Publication	Description
Dementia in Children, Teenagers and Young Adults - A guide for parents, teachers and care professionals.	This book addresses the dementia issues that many families experience, especially those who have children with JNCL. The book explains what can cause dementia, symptoms, and different therapy interventions. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
Therapy and Teaching with Batten Disease	A data source based on survey research with Australian participants. Investigates similarities of care, strategies used by parents, teachers and therapists. (Compiled by BDSRA Australian Chapter)
The Bumpy Road of Batten disease - A beginner's guide to getting Programs and Services	A beginner's guide to getting Programs and Services. (Amy Lombardi, MSW, LSW – BDSRA USA Family Services)
Medications	A compilation of medication most commonly used by children with Batten Disease. Includes anticonvulsants, antispasmodics, antidepressants, sedation, drugs for other problems. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
Respiratory System	A look at the respiratory system, what happens with Batten Disease and how to deal with some of the problems. (Nancy Carney, RN – BDSRA RN Medical Liaison/Educator)
Transition to Adulthood Checklist	Transition to Adulthood Checklist. (Amy Lombardi, – BDSRA USA Family Services)
Death & Dying: A Helpful guide in dealing with the many 'End of Life' Issues.	A guide in dealing with the many 'End of Life' issues (Amy Lombardi, – BDSRA USA Family Services)
How to Help Siblings Cope: A resource guide for understanding how siblings deal with grief and loss.	A resource guide for understanding how siblings deal with grief and loss. (Amy Lombardi, – BDSRA USA Family Services)