Frontotemporal dementia – some suggested resources

**What if it’s not Alzheimer’s: a caregiver’s guide to dementia**
This book is a comprehensive guide dealing with frontotemporal degeneration. Beginning with a focus on the medical facts, the first part defines and explores FTD as an illness distinct from Alzheimer’s disease. The next section on managing care examines the daily care routine including exercise, socialization, adapting the home environment, and behavioural issues. The final section focuses on the caregiver, in particular the need for respite and the challenge of managing emotions.

**Frontotemporal dementia** / Miller, Bruce L., (2014)
Frontotemporal Dementia provides an in-depth look at the history, various types, genetics, neuropathology and psychosocial aspects of one of the most common but least understood causes of dementia, frontotemporal lobar degeneration, from one of the world’s leading centres for the study of dementia.

**The dance: our journey through Frontotemporal Degeneration** / Deborah G. Thelwell (2014)
The Dance is a lively memoir of a couple's five-year journey through a little-known, non-Alzheimer's dementia - Frontotemporal Degeneration (FTD). Deborah and Alan's story is told with honesty, humor and love. The Dance illustrates of how the 'normality' of Deborah and Alan's life was stolen away by FTD. How they handled this challenge together and with the help of their family and friends shines some light on this uncommonly diagnosed disease.

**Where the Light Gets in: Losing My Mother Only to Find Her Again** / Kimberly Williams-Paisley
Many know Kimberly Williams-Paisley as the bride in the popular Steve Martin remakes of the "Father of the Bride" movies, the calculating Peggy Kenter on "Nashville," or the wife of country music artist, Brad Paisley. But behind the scenes, Kim's mother, Linda, was diagnosed with a rare form of dementia that slowly took away her ability to talk, write and eventually recognize people in her own family. Where the Light Gets In tells the full story of Linda's illness called primary progressive aphasia from her early-onset diagnosis at the age of 62 through the present day.
Green vanilla tea / Marie Williams (2013)
When Marie Williams' husband Dominic started buying banana Paddle Pops by the boxful it was out of character for a man who was fit and health conscious. Dominic, Marie and their two sons had migrated to Australia to have a life where they shared more family time -- when gradually Dominic's behaviour became more and more unpredictable.

Green Nails and Other Acts of Rebellion / Elaine Soloway (2014)
Early in 2009, after more than a decade of marriage, Elaine Soloway's husband, Tommy, began to change, exhibiting inappropriate behaviors at times, becoming inexplicably weepy at others. More troublesome, he began to have difficulty finding words. Ultimately, Tommy’s doctors discovered that he had frontotemporal degeneration a diagnosis that explained Tommy’s baffling symptoms and transformed Soloway from irritated wife to unflappable, devoted caregiver in one fell swoop. In Green Nails and Other Acts of Rebellion Soloway documents Tommy’s deteriorating health and eventual death, shedding light on the day-to-day realities of those who assume the caregiver role in a relationship with uncompromising honesty and wry humor.

Activities for the Family Caregiver: Frontotemporal Dementia/ Scott Silknitter, Vanessa Emm and Robert Brennan
This book offers information and insight to enhance quality of life through improved social interactions as well as activities of daily living, safety and general caregiver information. Learn new communications and activities strategies to improve time spent with your loved one. Discover how to turn daily activities and routines into opportunities to start some joy.

DVDs

Understanding Frontotemporal Dementias / with Teepa Snow (2014)
Frontotemporal Dementias (FTDs), an umbrella term for a range of disorders affecting the frontal and temporal lobes of the brain, are particularly challenging for families and professional caregivers. Odd, often impulsive behaviours and potential loss of language are just a few symptoms causing frustration and anxiety.

Looks like Laury sounds like Laury / By Pamela Hogan & Connie Shulman (2015)
What would you do if you started to disappear? At the age of 45, our friend Laury Sacks, an ebullient actress and the doting mother of two small children, had a reputation as the quickest wit in the room. At the age of 46, she began forgetting words. Soon she could barely speak. Our film, Looks Like Laury Sounds Like Laury, captures one year in the long, but short journey of frontotemporal dementia, a little-understood disease that strikes people in the prime of life. It is the profoundly personal portrait of a woman who is facing the unthinkable.
Online resources

Alzheimer’s Australia Video: [What is Frontotemporal dementia?](#)

Articles

Living well with progressive non-fluent aphasia by Jane Twigg and Jenny La Fontaine, The Journal of Dementia Care, Vol. 24, No. 5, September/October 2016, p.16-18

Jane Twigg has a rare form of dementia but her battle to get a diagnosis was fraught with difficulties. Here, supported by Jenny La Fontaine, she offers some advice for professionals.

Creative support for complex needs: living with bvFTD by Jenny La Fontaine, Anna Buckell and Jan Oyebode, Australian Journal of Dementia Care, Vol. 4, No. 2, April/May 2015, p.23-26

In the first of two articles on behavioural variant frontotemporal dementia, Jenny LaFontaine, Anna Buckell and Jan Oyebode explain the distinguishing features of this rare type of dementia and suggest a range of ways of offering individualised support.

Family experiences and needs: living with bvFTD by Jenny La Fontaine, Anna Buckell, Jan Oyebode and Jayne Ford, Australian Journal of Dementia Care, Vol. 4 No. 3 June/July 2015, p.24-27

In the second of two articles on behavioural variant frontotemporal dementia, the authors consider the families who live with the condition, and their support needs.


Myra Lamont shares the story of her husband Archie’s altered diagnosis – from Alzheimer’s disease to semantic dementia – and the lack of professional awareness and support they have encountered along the way.
Resources for children

What about the kids? Frontotemporal degeneration: information for parents with young children and teens  
Association for Frontotemporal Degeneration (c2012)  
This booklet’s goal is to assist families like yours to navigate successfully FTD's diagnosis, challenges and changes. Furthermore, this booklet aims to reassure you, the well parent. Children and teens can become resilient and confident adults despite—and often as a result of—adversity. Your strength will help your children feel safe and will show them how people who love each other help one another in tough times. No one welcomes the changes that FTD brings. Yet, hidden within the loss is the potential for unexpected positive growth.  

Frank and Tess – detectives! A children’s activity book about frontotemporal degeneration (FTD)  
Chow, Tiffany & Elliot, Gail ([2012])  
Frontotemporal Degeneration also FTD, is an illness that affects the brain. This activity book was created to children, ages 5-9, who are living with parent affected by FTD. Although every person and family experiences FT in a unique way, this activity book introduces situations that may be familiar to those who are living with FTD. Our goal is to provide valuable, age appropriate information about FTD and offer some helpful coping skills for children. Many of the activities have been specifically designed for the child of a parent with FTD to do together. To reinforce lessons in the book we encourage both parents to engage in the activities.  
http://research.baycrest.org/files/Frank-and-Tess-Detectives-.pdf

OUR LIBRARY CATALOGUE  dementialibrary.org.au

OUR DEMENTIA RESOURCES BLOG  dementiaresources.org.au