

Title: Parenting a Child with or at Risk of Genetic Disorders. Peter D Turnpenny, Dorothy Marsh and Sarah Lucas British Association for Adoption and Fostering London 2014 107pp £7.95 ISBN 9781910039052

Written for prospective adopters and carers, this slim volume does not aim “to provide all the answers about a specific diagnosis, but to lay out some principles about clinical genetic approaches to medical problems as they affect the adoption process” (p.31) Section 1, written by Turnpenny, a consultant clinical geneticist, describes how genetic disorders are passed through families; in Section 2, Marsh and Lucas recount their experiences of adopting children with genetic disorders. The key messages are clear: the implications of certain genetic conditions can only be explored by investigating birth parents’ medical conditions and sometimes wider family members’, a process which can prove highly problematic in adoption cases. Recording and sharing information about health is crucial. Diagnosis may help adopters secure appropriate support for their child and clarify any risk of the latter passing on the condition to their own children; when diagnosis occurs post-adoption, then information may need to be passed back to birth parents and siblings. Adopting a child with a genetic disorder can be a roller coaster experience - but the highs outweigh the lows.

Section 1 usefully clarifies some common misconceptions about genetic conditions but parts of it become quite technical, eg, a discussion of mendelian, non-mendelian and mitochondrial inheritance. While trying to explain these in lay terms, Turnpenny assumes the reader has a working knowledge of how chromosomes, genes and DNA work: I don't and I struggled to follow some of this. At other times the information given may be overly general to be of great benefit to adopters, with frequent references to a range of possible outcomes/ risks associated with different inheritance pathways.

In Section 2 Marsh recounts her family’s experience of adopting a three year-old girl with ‘developmental delay’, initially attributed to severe neglect but it later emerged that she (also) had growth hormone deficiency. Lucas and her husband adopted a baby with Downs Syndrome, one 7 year-old with profound learning disabilities and another with cystic fibrosis. Various common themes emerge from the two accounts: a sense of ‘falling for’ the child from the start; a steely determination to overcome many difficulties over the years, whether related to the child's condition, delays in getting diagnoses and medical information, or the constant fight for support.

I was a little perturbed by glimpses of negative perceptions of birth / disabled parents at times: eg: disapproval is implied about a couple with learning disabilities, whose first child was adopted, having another baby.

There are veiled references in Marsh's account to relationships with their birth children having suffered as a result of their decision to adopt but this is not elaborated.

Despite some reservations, this book will certainly be of interest and value to prospective and current adopters, particularly in its account of the challenges encountered and how many of these were successfully overcome.