BOOK REVIEWS

Sexuality and fertility issues in ill health and disability: from early adolescence to adulthood

Edited by Rachel Balen and Marilyn Crawshaw.
Published by Jessica Kingsley Publishers, UK,
2006, £25.00 (paperback), pp 304. ISBN 1-84310-339-7

"Let's talk about sex baby, let's talk about you and me; let's talk about all the good things ..." sang Salt and Pepper in 1991. But it's not just a pop group named after condoms that talk about sex. Everything from teen magazines to beer adverts does, such that *everyone* seems "at it"! However, society avoids discussing people

whose "normal" sexual and fertile experiences are obscured because of chronic illness or treatment. They are marginalised into a taboo niche. This book is unique in addressing, and thus legitimising, these experiences and so empowering those affected.

The book's transatlantic, transprofessional authorship adds a rich mixture of knowledge and practical experience. The text is well indexed and, with 27 pages of references, grounded in research and theory. The book opens with a clear outline and who it is focused for—caregivers, professionals, family and friends (disappointingly it misses the usefulness it could provide for the people it describes).

The book starts by recognising early adolescence as a time of great flux mentally, emotionally and physically for all youngsters regardless of health. It acknowledges how sex, fertility and parenting develop on young people's agendas while the experience of illness is an additional dimension some have to contend with.

The book's second part has a four-pronged approach tackling medical, scientific, legal and ethical aspects of sexuality and fertility for young people with ill health and disability. This is rather medicalised but very comprehensive. Particularly interesting are chapters on egg and sperm preservation and fertility restoration. They would equip those counselling young people on the methods and chances of conception.

The third part focuses on research of ill young people's personal experiences of sexuality and fertility. An excellent chapter actually addresses this issue in the context of black and ethnic minorities (albeit only one page is devoted to developing successful fertility services).

The book's last section is written by young people and their parents affected by illness. These chapters provide insight into their "worldview" although their brevity makes them seem an afterthought.

The whole book is littered with an excellent wealth of qualitative data addressing areas such as: childbearing and fertility being the main concern for some rather than sex per se; contending with the implications of genetic conditions while only a teenager; rationalising that for some becoming a parent means adoption; coping with disease recurrence after having children and the associated ramifications.

A few example vignettes include one infertile man who hence thought he had no need for condoms but did not appreciate their protection against STIs. Another expresses anger at having to have invasive fertility treatments because of previous chemotherapy. Doctors do not escape comment. It was embarrassing to read of a 12 year old girl who needed repeated vaginal dilation, whose doctor never explained to her why.

It was good that the book covered topics like polycystic ovarian syndrome, Turner's syndrome, cystic fibrosis, congenital adrenal hyperplasia, HIV and post chemotherapy that probably do not automatically spring to mind when thinking about disabilities. However, my main criticism is that it left out those with learning disabilities. Though this is a heterogeneous group, some have a sufficient IQ to explore their sexuality even if their IQ might compromise parenting. (Perhaps this was too controversial to tackle!)

Overall, I recommend this book even in spite of my criticisms. The chapters are well written and so complete that they can be dipped into any time. Acquiring a copy will go some way to addressing another issue raised by it—that some paediatricians feel uncomfortable talking about sex and fertility with their patients. This book will enable people to instead say, *"Let's talk about sex!"*

S Haroon

Human malformations and related anomalies, second edition

Edited by Roger E Stevenson and Judith G Hall.
Published by Oxford University Press, Oxford,
2005, £180.00 (hardback), pp 1495. ISBN 0-19-516568-3

Although the title of this book, *Human malformations and related anomalies*, sounds familiar, in fact it is quite original. There are many books exploring areas of "genetic" and "congenital" human body abnormalities, but those resources addressing

the anatomical perspective of human defects are actually few.

It is a real textbook with nearly 1500 pages of pure, concentrated and concise information, covering the enormously broad spectrum of human malformations.

With 44 contributors (all but one from North America), who belong to eminent institutes, one would expect a very comprehensive standard of core information, and indeed it is. Through their preface, which mainly briefs developments in the field over a decade (since the previous edition), the authors could push the "warming-up" reader to a very "hot" start.

Considering the anatomical perspective of the book, the divisions and subdivisions of the text to chapters based on various body systems is quite reasonable. I've been really surprised by the quantitative variety of malformations that might affect organs, such as the tongue and the umbilical cord. I have to say that the most valuable parts of this book are the first chapter, which included nomenclature, classification, aetiologies, in addition to management, and the

index of tables of malformations and associated syndromes which is a precious reference treasure for any paediatrician. I would have been equally impressed with the first chapter only if there were more detailed discussions of the issue of counselling the parents.

Adequate use of the current imaging technology is obvious in more than illustrations to support the text. Well presented examples include the electron micrographs showing the embryology of the spleen and that of the external genitalia. Yet, the absence of a single coloured picture in a 2006 second edition of a textbook of human malformations is a defect in my opinion. Despite the richness of the first part with figures, graphs, flow charts, and pedigrees, many of the following parts are very poor in such illustrations—a deficiency which makes the dense text boring, brain-tiring, hard to understand, and imperfectly presented, especially in areas with complicated genetic aspects.

As in any textbook written by a number of experts who belong to different schools and subspecialties, there is an expected inevitable variability in the style, clarity, simplicity/complexity, organisation, and order of writing. In spite of my preference to unify at least the side titles of each chapter and their order, I appreciate the need for some freedom. Yet, I must mention that I enjoyed most the simpler, more organised and precise chapters. Of special note in this aspect I will memorise the chapters discussing malformations of the heart, skull, ear, nose and limbs.

In short, despite the imperfection in some ways—especially as regards the presentation of information—I consider this book a distinctively valuable resource on the shelf of any neonatal unit for the generosity of its core information.

Y A H Negm

Management of disorders of bladder and bowel control in childhood

Edited by A von Gontard and T Neveus.
Published by Cambridge University Press,
Cambridge, 2006. £65.00 (US \$115.00) (hardback) pp 355. ISBN 189868345X

I love poos and wees, so you can imagine the difficulty I had controlling my own bowel and bladder during the time I was waiting for this book to arrive. I must confess to some degree of professional competitiveness, which made me want to find fault with it wherever I looked.

I have to report mixed success—I did remain continent, just, but the book itself is actually a bit of a treasure trove.

It is difficult to imagine a better-researched volume. It explores all aspects of bladder and bowel physiology and pathology and discusses the management of these problems in a sensible and humane way. The text is detailed but very readable and although it describes some fairly eye-watering investigations and treatments, it does emphasise that these are rarely needed.

As healthcare professionals, we underestimate the impact that these conditions have on children and their families. They really do take

over their lives yet our response is largely dismissive. One of the pleasures of working with these families is to see how starting treatment revolutionises their entire world.

If you don't believe me, consider how assiduously families fill in poo and wee charts compared to how they fill in blood sugar charts (sounds like a good idea for an audit to me). This book contains a number of useful charts and event recording charts—there are more attractive ones readily available.

Families with children with voiding disorders frequently want to know “Is it all psychological?” as if the mind and body are two entirely separate entities. This book nicely explores the overlap between functional and organic showing that these are conditions of the whole child, meriting a holistic approach.

I might take some issue with the timing of formal psychological support as I often find that making the symptoms go away by physical treatments causes much psychological morbidity to simply evaporate.

Obviously I am allowed a few gripes. Although the book nicely emphasises the importance of history taking, it does not do this in a challenging way. For example, I find that when a soiling child says “I didn't feel it coming or know it was there”, they invariably mean “I didn't want it to come, but I did know that it was there”.

There is no mention of the fact that much soiling occurs because of postponing voiding—because children are too busy watching TV, using computer games or occasionally even indulging in the archaic pastime of normal play.

There are a few too many enemas and not quite enough fibre for my liking, and I don't know any families that could get a child to sit on the toilet the oft-recommended three times a day. The use of laxatives may be a bit proscriptive; I like to aim for a soft, easy, regular stool regardless of the dose required.

This is clearly a book for the connoisseur. It is too detailed to be a general handbook (albeit that it lacks in such basics as how to sit on the toilet properly). My enthusiasm appears not to be infectious so my colleagues largely felt that they would be happy to let me read it and tell them about the “good bits”. Despite what I have said above I think it is jam packed, even impacted, with good bits. It is fantastic to have access to so much information, which is so clearly authoritative but sometimes a bit tricky to navigate.

If you are interested in this area you will cherish this book as a rock, and if you are not hooked yet, then I pity you, but suspect you will not put this on the top of your reading list. I have left it on my desk, and colleagues or trainees—oblivious to their own loss—have, mysteriously, not taken it.

As an afterthought the cover shows a worried girl in bed with a wolf. I will steer clear of Freud, but wonder if the wolf is an allegory for, or the cause of, the poor girl's night-time wetting.

Anthony Cohn

Working for children: the development of the Paediatric Unit at Northwick Park

B Valman. Published by The North West London Hospitals NHS Trust, 2006, pp 144 (hardback). ISBN 0955293502

Working for children encompasses the past, present and future of paediatric services at Northwick Park. It is clearly written by Dr Bernard Valman, who readers of a certain age will recall was a co-editor of the *Archives of Disease in Childhood* with

Professor Sir Roy Meadow. His experience as an editor, which I still greatly appreciate in my “growing up” as a paediatrician, is reflected within this impressive book.

He frankly recounts the challenges and rewards of multiagency cooperation and describes the challenge of setting up and maintaining a paediatric unit in a non-traditional University teaching hospital. It is a book which I believe should be read by anyone interested in the practicalities of trying to set up and run services.

As a district general hospital with a Clinical Research Centre, the Paediatric Unit at Northwick Park at its foundation in 1969 was a unique institution. What an opportunity—and, with hindsight, we can now appreciate how fully this was taken by its paediatric staff, given the list of eminent alumni who passed through its wards and who were clearly positively influenced by the academic unit's policy of curiosity and rigorous scientific enquiry.

The list of publications and major research projects demonstrates that this was not an academic centre, a claim which can seem to be too commonplace nowadays where some centre's members profess areas of interest but within them are conspicuously light in terms of research publications and presentations.

We grieve on reading of the short-sighted decision to close down this Clinical Research Centre and share the author's anger when he relates how there was no discussion with the paediatric department who were presented with this fait accompli.

The Paediatric Unit was however made of sterner stuff. It picked itself up and as the book relates, has moved triumphantly on and is still conducting research. From the 1990s Northwick Park became associated with St Mary's Hospital, London and received significant investment in medical education and the appointment of a senior lecturer.

As the founding consultants retire we are reassured that with the present consultants, affectionately termed the “Young Turks”, the department is in safe hands.

The lesson for us is that in spite of setbacks, the department has continued to grow and develop new and relevant paediatric services.

This book is a manual on how a department survives, thrives and ultimately triumphs against considerable adversity

There are also little gems within the book such as the correspondence between Donald Court (of the Court report) and the author himself, which alone are worthy of a review. From the comments that “it is amazing what a revelation ‘social paediatrics’ is to the cellular paediatrician” of July 1980 to an extremely candid report of February 1984, summarising how a children's department “plainly carrying an excessive load” yet so underresourced that “the equipment of your special care baby unit is now almost totally dependent on voluntary sources of money”, still managed to show its mettle. How the Northwick Park department moves forward to protect what it has and to lay the groundwork for successful commencement of innovative services in the future are templates that I believe will continue to be of relevance for those responsible for these services.

The back cover statement that “the successes and failures experienced during this process will be of interest to all those who wish to improve the care of children and their families” succinctly emphasises what I see as its true strength.

It doesn't say it, but I believe this book is a manual on how a department survives, thrives and ultimately triumphs against considerable adversity. It emphasises how paediatricians need to seek management positions within their employing Trusts in order to ensure that children's services are represented, how they must network and advocate effectively, and lastly that they must willingly accept independent reports and recommendations to keep the service moving forward. For this reason alone, as a sort of paediatric “What is to be done”, I would recommend this book.

Reading this book inspires us to look at our own departments and to see what more we can learn to improve the lot of our local children and their families.

The late twentieth century will be seen as a time when important interventional governmental policies, several controversial and major reports, the establishment of the Royal College of Paediatrics and Child Health, the National Service Framework and the appointment of Children's Commissioners were decisive and positive factors in the management of children. This book will play an important role for future historians in viewing these events.

Finally I hope that other readers of this book will be inspired to record their department's histories, so that the available source material of future medical and social historians will not, apart from Northwick Park, be restricted solely to that from considerably richer and more influential university teaching hospitals.

A N Williams

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