
Preface

Art is long, and Time is fleeting,
And our hearts, though stout and brave,
Still, like muffled drums, are beating
Funeral marches to the grave

The Reaper and the Flowers
Henry Wadsworth Longfellow

Two of us, John M. Hutson and Garry L. Warne, have spent our entire careers looking after patients with disorders of sex development (DSD). And as in all human interactions, we have learnt as much as we have taught. DSD present a specific combination of difficulties for clinicians grappling with their management: they are both extremely complex as well as rare, making acquisition of expertise a unique challenge. It was obvious in the 1970s that concentration of clinical experience with these conditions into a small group of committed doctors was a way to gain and then retain the special knowledge needed to provide these people with the best care – optimal medical and surgical treatment, appropriate counselling as well as moral support and empathy. Nearly everything we have learnt has come from our patients and for that we are extremely grateful. This volume is an attempt to preserve all of this knowledge for the next generation of patients and clinicians coming to terms with DSD.

The book contains many special features which we hope the readers, clinicians, parents and patients alike will be able to benefit from. We have tried to make the embryology of sex development understandable, and many of the chapters contain numerous diagrams that aim to make what to many people is an invisible mystery not only visible but also comprehensible. This emphasis extends to the chapters describing how to work out the diagnosis, as this is much easier when one understands the embryology. This culminates in Chap. 11, where we describe the ‘rules for clinical diagnosis’, which have been invaluable to us, as can be used by others also.

Another feature of the book is the clinical photographs of the anatomical details. Unlike the previous generation of endocrinology textbooks, there are no full frontal nude photographs of patients, being treated like ‘specimens’. We learnt from our patients how much they hated being treated like a ‘freak’, and full body photography crosses this line. Instead, the photographs, that doctors need to learn about the disorders, are all close-up images of the genitalia and or perineum, with no identifying features about the individual patient. We hope our patients will understand that this special part of their anatomy needs to be seen by doctors, so that they can learn.

Gender assignment and the possible need for surgery in infants is a very controversial issue, and we have a chapter on all the ethical issues. Importantly, it describes

the ethical principles we use to assess the proposed medical plan at birth, which have been endorsed by an international group of Family Law experts. It also includes our current algorithm for ethical assessment of medical plans in the neonatal period, so that there is a robust framework for these life-changing decisions.

Many DSD do not present until late in life, and the book contains a special section to describe these, so that clinicians can (hopefully) use these chapters to help resolve the underlying problems.

Babies with genital anomalies soon become children adolescents and adults, and we have put a lot of effort into providing chapters on all the issues that arise. In our chapter on DSD in childhood, we have a section on how to talk to pre-adolescent girls with Complete Androgen Insensitivity Syndrome (CAIS). This should be extremely useful to doctors struggling with the problem of how to broach the issues of XY chromosomes in a girl.

Finally, there are chapters on the long-term outcomes and the cultural differences of how DSD are seen in different societies. We end the book with a chapter written specifically for parents of a child with CAIS. This first appeared in the 1990s as a small booklet, but has been so much in demand we have reproduced it here, to ensure it remains available to parents hungry for information in the future.

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An Integrated Approach to Management

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