



The Other Side of Pediatrics

A guide to the everyday
care of sick children

June Jolly

THE OTHER SIDE OF PEDIATRICS

A Guide to the Everyday Care of Sick Children

June Jolly, SRN, RSCN

Illustrated by Gillian Simmonds, ARCA



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The Other Side of Pediatrics

To sick children everywhere and
to all who have made this book
possible: patients, families and colleagues

Foreword

June Jolly is a nurse, a children's nurse, who has seen a great deal and felt a great deal. After many years of watching the hospital scene she has attained that rare thing, a capacity for understanding what is going on in a child of any age, what he is thinking or feeling and what he needs. She began by studying social sciences and then became a Child Care Officer. She spent twelve years in this arduous and often heart-breaking work. Her insights into family life drew her more and more towards the child himself and then to that special corner of childhood — illness and the hospital.

One of her earliest appointments was that of Night Sister at St. Christopher's Hospice. She has therefore experienced the nursing of people at the end of life, some of whom are about to leave it, as well as those at life's beginning. She has been a children's ward sister at St. Thomas's Hospital, London and the Brook General Hospital. In these posts with her great experience and knowledge of social work and family problems she was able to teach a new approach. A 'child', whether baby, toddler or of school age, is one part of a coherent whole — the family.

The long tradition (before Platt and even since) of viewing the child and handling him just as a very demanding little adult, had to be modified. It has, of course, always been the endeavour of paediatricians to inculcate in all hospital personnel a respect for the child's individuality, but June Jolly shows that it is only through taking him together with his family that this individuality can properly be seen.

Everything in this book is a record of the direct observation and experience of the author. What a refreshing story it is! Sweeping out old hide-bound ways of looking at things and obsessional adherence to traditional practices, and illustrating every point from her marvellous collection of examples. The first requisite of any treatment, she reminds us, is that it shall do no harm. We know we do harm, or at

any rate cause suffering additional to the illness. We, the doctors and nurses, justify our rigid attitudes by pointing to the many dangers of the passage of a child through a hospital — anaesthesia, potent drugs and exactitude of dosage, cross-infection, accidents, exposure of children to sights that would be better concealed from them, and so on. But one does not find in this account of the handling of the sick child that any of these dangers are forgotten or that strictness for safety is disparaged; only that we can be understanding, liberal, relaxed and tolerant, and still be safe.

The book is written primarily for nurses (though by heavens the doctors and surgeons need it too!) and with the principal hope that it will help them to acquire, before during or after training, a *new attitude*.

Nurses experience early in their training that in giving their skill to adult patients, by their unselfish work, they evoke gratitude and affection in return. Children have no notions of gratitude (till they are much older), but nurses often sense the warm response of the child to whom they have given some specially understanding care. It is one of the unasked-for rewards of devoted people. But the new attitude is one which takes into account a much broader concept of the child to whom she will give this understanding care.

A child is dependent on his parents whether they are present or absent, and the very young child is utterly dependent. The nurse who can give her concern not just to the particular stress or need of the moment, but, as it were, beyond the child to all his 'appendages' — his parents (absent or present), brothers, sisters, school teacher, cat, possessions; his world in fact — she has the new attitude.

Family centred care is June Jolly's name for it.

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Preface

What is the other side of paediatrics? For years it has been the accepted practice to nurse children in isolation from their families, their friends and their environment. Physical treatment has been excellent and staff have lavished much tender loving care on their patients. Every year medical and technical advances have made medical prognoses even better. But something vital has been missing. It is only in the last twenty years or so that attention has begun to focus on the child's other needs: for him to have his family, and more particularly his parents, with him at all times; room and freedom to play; access to education and facilities to meet his developmental requirements. Providing for these in a hospital setting required changes of approach, attitudes and expectations of staff and patients. Administrators too need to be involved in planning and providing a different kind of facility for children. It is this that I have called 'the other side of paediatrics'. It is so essential that one could well call it 'the human side'.

This book is written primarily for my fellow nurses as they have the 24-hour care of the children. It is their attitude that will determine how much families are really included in the care of their sick children. They create the atmosphere — whether welcoming and warm or clinical and cold. With skill and inclination to communicate at a child's level, a nurse can add enormous support to young patients and, in doing so, greatly increase her own job satisfaction.

Throughout the following chapters I have endeavoured to share my experiences over the years as I have struggled to respond to the sick children I nursed, who always wanted more than just to have their bodies mended, their diseases cured and their handicaps eased. It is my hope that it will be an encouragement to see that it is possible, gloriously possible, to meet these needs within an ordinary paediatric ward. If it also stimulates new ideas and innovations, and

nursing staff to be more ambitious and courageous in overcoming obstacles, it will have been worth all the effort. It is because of this that I have tried to concentrate on practical issues including many of the everyday problems that may be encountered. I have also tried to suggest practical solutions, drawing on the experience both of colleagues and in a few instances describing specific projects designed to meet particular problems.

In 1974 I was privileged to receive a Florence Nightingale and Rayne Foundation Scholarship, which enabled me to visit many centres throughout Canada and the United States – North American experience is referred to in a number of chapters. References to the centres visited are recorded at the close of the chapter concerned.

This book is divided into three parts: 'New Approaches to Sick Children', 'Meeting the Needs of the Whole Child' and 'The Ward Team'. Although one might have expected to start with the needs of the child, it seemed important first to set the scene in which the new approach to sick children has been made, and then to establish the main concept of that change – family-centred care (Chapters 1 to 3).

In order to understand the needs of the child, a basic knowledge of child development is essential. For example, the process through which children under three years' old relate to adults is very complex. They are unable to relate to any adult except as a 'mother', and when a succession of adults take on the caring role the child attempts to develop such a relationship only to be passed on to another. Thus the anguish of losing the mother can be repeated many times over. If more nurses and doctors were aware of this problem there would be more support for ensuring that whenever possible young patients were not separated from their mothers even for short spells of hospitalisation.

One chapter is devoted to play because of the importance children attach to it, and specific 'hospital' play is discussed, as well as the types of play most acceptable to children with certain conditions. As communication with children of various ages is somewhat specialised, this is also discussed in a separate chapter. The need for the right environment and how to create it is the topic of Chapter 7.

Finally, Chapters 8 to 10 are devoted to the ward team — its functioning and organisation from the staff point of view. Students may not be prepared for the differences in paediatrics, for example, and the challenges this may bring. Moreover, the ward team may include a number of specialists of various disciplines and approaches to children. Their different functions are identified in the hope that their expertise will be better utilised and their place on the ward team ensured. These specialists may include the nursery nurse, the play specialist, the school teacher, the liaison health visitor, social worker, physiotherapist, occupational and speech therapists, dieticians, and district or community nurses. These 'specialists' join with the nurses and doctors, auxiliaries, receptionists, orderlies, ward hostesses and housekeepers to create the ward team. In some areas the teams may be augmented by a ward granny, family receptionist and members of the psychological services. A formidable team indeed, and when one realises that a number of different doctors, nurses and auxiliaries may be involved in nursing an individual child, it is not surprising that the child and his parents can be somewhat bewildered by the vast array of new faces they meet whilst in hospital.

For this reason it is vital that attempts are made to limit the number of people involved in the care of any individual patient. Case assignment, but preferably *family* assignment, can mitigate some of the fragmentation of care. When all approaches to the child can be made through the mother, she effectively buffers the onslaught and can protect her offspring from much of the fear that is so often its accompaniment. This is particularly relevant in the light of one recent study (Hawthorn, 1974) which showed that in only one week's stay in hospital, children received care from as many as 17 nurses, while in the best unit observed it was never less than 10.

There are considerable numbers of children who are still nursed in adult wards because of adult-orientated surgeons and a few physicians prefer to have all their patients in one place. This may save a few steps for the busy specialists — but at serious costs for their young patients. While children continue to be nursed alongside adult patients it will be

extremely difficult and expensive to provide adequately for their special needs. Not only is it impracticable to provide the facilities necessary for many small groups of patients, but also the staff in these specialised units often remain unaware of the young patient's needs. Even if it is possible to include parents in some of the care, and provide living-in accommodation within the ward, it will be virtually impossible to change the timetable to suit a youngster, let alone to provide space for play, education and for maintaining good contacts with his peers and community events. The cost to the young patients is obvious. Children who are transferred from an adult area to a children's ward usually make better progress once they are in a place where they feel they 'belong'. The need for nursing children in paediatric wards is vital.

It has been my experience that this sort of enlightened care can be established and practised within the restraints and confines of general district hospitals, that the special needs of children do not have to be sacrificed to the needs of the majority, and that old buildings can be adapted, in some cases perhaps more easily than new ones. It is not a question of vast additional expenditure — in some areas, no new costs will be incurred, and in some there may even be savings. The main requirement is determination and perseverance by the nurses and other staff involved, backed by a sound basic knowledge of child developmental needs and enough imagination to see how best to use the resources available.

In most hospitals there are many improvements in child-nursing practice still to be made, often major improvements but awaiting only the vision and action of the staff involved. It is because of this that I share my experiences in the following pages. Nursing sick children is the most rewarding and satisfying job I know. Heartache, frustration, hard work there will be, but it can be such fun.

Hove, 1980

J.D.J.

Acknowledgements*

This really isn't 'my' book at all. Without the help and encouragement of my friends and family it probably would never have reached the printing press. Without my sister Gill's sensitive illustrations it might not have been understood. Her sharing not only in the message the book contains, but also in its communication, will, I hope, engender further ideas and innovations, in ways which will continue to improve care for the sick child.

It is therefore my joy to give honour where honour is due. To Jill Macleod Clark, whose enthusiasm first inspired and who then cajoled and generally bullied me into writing this book; to Margaret Atkin who burnt the midnight oil with me and gave me courage to go on when I really felt it was impossible; to Richard my brother and his wife Alison whose support and encouragement was there to fall back on at every turn; to my good friend and colleague Edna Anderson whose experience in the care of children and their families is now much greater than mine – I would like to give sincere thanks.

I am privileged to have had the professional advice and counsel of many notable people: James and Joyce Robertson who have given so graciously of time and expertise and who taught me much of my understanding of young children, especially those vulnerable 'under-threes'; Peg Belson, founder member of NAWCH – the National Association for the Welfare of Children in Hospital – with whom I have shared concerns for so long and to whom I owe more than I can say; Susan Harvey, who gave me many insights from her unique knowledge of play for sick children and lent me such valuable assistance over the years. My thanks are due too to Sally Huband, whose concern for paediatric nurses and their training I admire and who gave me much pertinent and

** Purely for the convenience of readers the pronoun 'he' has been used to describe children of either sex. For the same reason all staff are referred to in the female gender.*

practical advice. I cannot omit mentioning my dear friend Vivian who out of love, painstakingly deciphered all those scribbles and typed the whole manuscript so well, and Julie Robson who so patiently typed and retyped the final copy.

Lastly I want to pay tribute to Dr Dermod MacCarthy who has borne the brunt of revising the text, making suggestions from his wealth of experience with characteristic sensitivity, humility and meticulous care. It was he who first had the courage to include families in the contemporary care of sick children. To me it is the greatest honour that he should consent to write a foreword.

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