

BOOK REVIEWS

Autism and Loss by Rachel Forrester-Jones and Sarah Broadhurst, published by Jessica Kingsley Publishers, London and Philadelphia 2007.

This is an accessible and useful book for those working with people with autistic spectrum disorder. The format ensures that it is easy to read, with the first chapter presenting an overview of current developments, research evidence and theories within the field. Consideration is given to the complexities of loss, from those who experience significant loss through bereavement, but also those who experience the day-to-day losses associated with modern life. The reader is directed to consider how people with autism may have particular difficulty coping with loss as a result of the triad of impairments associated with autistic spectrum disorder. The authors emphasise that each person with autism is unique and the experience of the pattern of impairments will be specific to each person, whilst recognising some of the generic difficulties that are autism specific. This is a theme that is frequently reiterated throughout the book, to ensure that thought is given as to how to apply the content on an individual basis. The introductory chapter also raises awareness of the ethical and consent issues that may arise as part of the process of undertaking interventions with people who have experienced loss and offers some guidance on how to use the strategies recommended within the book in line with current Government advice.

The types of loss that may be experienced by adults with autism across their lifespan are examined within the book and five main types are presented, the loss of: social relationships; home and possessions; role and identity; health and wellbeing; and loss through death. For each type of loss presented, strategies are provided for assisting people with autism to understand the loss they have or may experience and how they may accept and live with that loss. The authors state that the book can be a resource for families, professionals and carers from different educational, professional and training backgrounds and this does indeed seem an accurate representation of the content. The book is well organised and provides background information for

each separate type of loss. Each chapter has fact sheets and worksheets that contain both written and symbolised information. The authors state that the fact sheets are primarily intended to provide information for family/carers/staff/supporters of people with autism. The worksheets have been designed for direct use with people with autism and contain practical exercises to provide a way to talk about and address issues, in order to promote positive coping. The fact sheets and work sheets can be photocopied, which allows the reader to freely use them in a way that is tailored to each individual who experiences difficulties in relation to loss. For each type of loss, brief case examples are given which highlight how the particular issues raised may be relevant to people with autism based on the triad of impairments and individual life experience. One of the worksheets stood out as being of particular benefit which raised the issue about what to expect and how to behave at a funeral, this would be invaluable in supporting people to cope in a situation that is socially and emotionally demanding. Another positive of the book is that the chapters could be used sequentially or in isolation depending on the area of loss that was or is being experienced.

While I was impressed with the practical approach taken within the book, I did find some of the information carrying aspects of the worksheets to be fairly complex and some individuals would need significant support to comprehend the materials. The front cover of the book indicates that the content is suitable for use with both children and adults, but I thought that some of the worksheets could be hard to access for those with more significant cognitive impairment. The worksheets do have symbols that should assist in facilitating comprehension, but all of the worksheets contained within the book do rely on the person with autism being able to readily use verbal or signed communication and to be able to communicate reflections on their feelings and experiences. I thought it would have been useful to have more consideration of how to address issues of loss with people with autism who find sophisticated verbal communication or self-reflection more difficult.

Overall, I would recommend this book as a great starting point for addressing the difficult topic of loss

with people with autism. The book addresses some of the generic issues associated with loss and in addition contemplates how the experience of autism may in itself create or intensify areas of loss, as the person with autism not only has to adjust to the loss, but also to the differences between themselves and others.

Rowan Crawley

Supporting the Child and the Family in Paediatric Palliative Care

Erica Brown with Brian Wark

ISBN9781843101819

“Supporting the Child and the Family in Paediatric Palliative Care” is an overview of the provision of care for children with life limiting conditions. This gives many practical pointers for their holistic care. The author is thorough in the discussion of all aspects regarding the needs of the children and their families. There are chapters dedicated to children’s understanding of and reaction to illness and dying, planning for end of life care and funeral services. The traditions and rituals of all faiths and none are noted and clearly explained which will help those involved to manage the situation with confidence, care, respect and professionalism. Attention is also given to the support of parents and siblings during illness and bereavement and refreshingly the author also notes the need for the supporting of grandparents who are sometimes overlooked while focusing very much on the parents.

The importance of viewing a child as an individual, with their own unique fears, questions and needs is emphasized. Useful practical help is offered on the support of children and families as they make difficult choices at very stressful times, this will be appreciated by all professionals working in this area.

As well as practical pointers the author also offers readers reflective pieces on various other topics such as the cultural, spiritual and secular aspects of

care. The effect of caring for a terminally ill child not only on the family but also the community is noted. The educational rights and needs of the child are raised, as is the transition of young people from children’s to adult services, a situation which is becoming more common with advances in care and medication, but which raises a whole series of new issues and implications. The author also enlists other writers to raise the ethics of organ donation and tissue retention.

Paediatric palliative care is still a relatively young discipline, with Helen House, the first children’s hospice in the U.K. recently reaching its 25th anniversary. There is still a good deal of misunderstanding regarding the role of children’s hospices who are generally more involved in respite care than terminal care. This book reflects the ethos of a place for living embraced by children’s hospices and underlines the importance of holistic care.

The author also looks to the future in the last section of this book, ‘The Way Forward’. Here the questions of quality assurance, standards of care, the place of research and development in the field of paediatric palliative care is examined and provides much material to digest and reflect upon. These are timely inclusions as many hospices are engaged in this work at present.

“Supporting the Child and the Family in paediatric care is a most helpful and accessible book. The author draws on her own experience of working in the Acorn Children’s Hospices to support her writing. The format of the text, with each chapter ending with ‘key points’ and ‘implications for practice’ is helpful and would allow readers to dip in to chapters as required. It is supportive to the work of those already engaged in the care of children and informative to those whose experience is limited. The multi disciplinary approach would make it a useful tool to all medical, pastoral or support staff.

Evelyn Cairns