



Peaceful, pain free and dignified: palliative and end of life care .

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Book Review

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3 Ferguson J, Laurie V. Peaceful, pain free and dignified: palliative and end of life care for people on
4 the autism spectrum. A guide for social care practitioners. 2015 BILD Publications.

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6 ISBN: 978 1 905218 41 7
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10 This book aims to provide advice and support for people involved in the care of people on the autism
11 spectrum as they face terminal illness and end of life. It is based on the experience of a team who
12 did support a person (Stephane) with pancreatic cancer and, throughout, the experiences and
13 comments of all involved – family, carers, nursing staff, doctors and his house mates – are used to
14 illustrate the various aspects of care. This gives a reality to the discussion and helps to bring the text
15 to life.
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18 There are short descriptions of both autism and palliative care and, although this book is aimed at
19 social care professionals, it would be very helpful for anyone caring for a person on the autistic
20 spectrum. The complexity and difficulties of assessment and care are explained clearly, as well as
21 reinforcing the need to be with each individual and look at their particular needs and concerns.
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24 There are excellent sections on the different aspects of care. In the discussion of physical
25 assessment there are clear explanations of the use of specific tools to help assess someone who may
26 not clearly communicate their pain or needs. As anyone faces the end of their life there is the need
27 to look ahead and within all populations this is often put off and ignored. With a person with
28 communication issues and who may process information differently, this may be a particular
29 challenge but the authors do take this up and suggest ways of listening and responding to an
30 individual's wishes and aims.
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33 The challenge of accessing the voice of the individual is also considered when discussing
34 psychological issues– considering the differing ways of thinking and responding to the world around
35 them, different ways of processing and understanding information and the possibility of anger and
36 frustration as someone becomes less able physically. These issues may be seen within social care, as
37 there may be profound difficulties in social understanding and although no response may be
38 outwardly evident the person may be greatly affected by stress and worries and the changes and
39 concerns around them. The problems that may arise with communication with others – family and
40 professionals – are addressed and the complexity of discussion of the same issues with the person,
41 the family and other professionals in different ways is considered.
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46 Spiritual care is often discussed within palliative care, although there is frequent confusion and a
47 lack of real understanding of these very personal and complex issues. For a person on the autistic
48 spectrum the need for a personal approach and careful listening to where they are is encouraged.
49 There may be certain spiritual or religious aspects of care that may be very helpful, but the authors
50 also stress how carers may gain a great deal from listening to the people they are caring for – it is
51 not a one-way communication.
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54 Throughout the book the use of the comments and experiences of the team caring for Stephane are
55 very helpful in reinforcing the messages. There are excellent summaries at the end of each chapter,
56 summarising the main points. This book would be very useful for any team caring for a person on the
57 autistic spectrum –not just within social care but also within hospitals and hospices. The support of
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3 the team is stressed throughout as is the importance of all involved being aware of their own
4 feelings and responses to the dying person. As the authors suggest, although it is people on the
5 autistic spectrum who are often seen as having problems coping with change and transition, this
6 may also apply to professional carers and they support McCreadie's suggestion to "put your own
7 oxygen mask on first", so that carers are prepared themselves and then able to help others.
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