



# Palliative Care for People with Learning Disabilities





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# Palliative Care for People with Learning Disabilities

edited by  
Sue Read





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# CONTENTS

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List of contributors	vii
Foreword by Linda S McEnhill	ix
Preface by Dr Sue Read	xi
Acknowledgements	xiii
1 Historical perspectives — care for people with learning disabilities over the past century <i>Michelle Persaud</i>	1
2 A troubled past and present — a history of death and disability <i>Stuart Todd</i>	13
3 How did you cope? Learning from case studies in death and dying <i>Jacqueline Furniss, Heather Morris, Sue Read</i>	27
4 Pain and symptom management <i>Claud Regnard, Charlotte L Clarke, Lynn Gibson, Dorothy Matthews</i>	39
5 The role of the learning-disability nurse — meeting individual needs <i>Siri Persaud</i>	57
6 Ethical decision-making <i>Karen Ryan, Regina McQuillan</i>	75
7 Communication in the dying context <i>Sue Read</i>	93
8 Counselling and support <i>Sue Read</i>	107
9 Spirituality, suffering and palliative care <i>John Swinton</i>	121
10 The role of hospices <i>Linda S McEnhill</i>	137
11 Research, palliative care and learning disability <i>Edward Lindop</i>	153
Index	167





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## FOREWORD

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So strong are the joint taboos of death and disability that it frequently comes as a huge surprise to organisations and carers when one of their service users becomes terminally ill and dies; or dies suddenly, as is more often the case. Services may in hindsight realise that the signs and symptoms of the illness were there for some time, but unseen until the end. Often, this becomes the source of deep regret which, when defended against, does not facilitate the type of changes necessary to ensure that ‘history’ does not repeat itself. This book is written for services, policy-makers, students and individuals who either proactively wish to avoid such a situation or, having experienced it, wish never to do so again. Its importance, therefore, cannot be underestimated.

It is a huge privilege to be asked to write the foreword for this book as it forms something of a landmark in an almost barren landscape. As the editor’s preface says, it is a ‘first’ in bringing together the emerging knowledge held by a small group of academics and practitioners in this developing field. It is again testimony to the power of these taboos that, although authors such as Sinason, Hollins, Cathcart and Oswin laid the foundations for our thinking about the impact of death on people with learning disabilities (albeit from a bereavement perspective), it has taken some decades for others such as Tuffrey and Blackman to arise and build upon that knowledge-base. In the interim period, we have learned that people with learning disabilities not only grieve but also die. No longer hidden away in long-stay hospitals, people with learning disabilities and their dying have become public issues. Yet it is clear that the taboos are alive and well and consequently mainstream services are singularly unprepared to meet the often complex needs of this client group at the end of their lives.

It is therefore particularly appropriate that Persaud’s chapter should open this book by recontextualising us with a historical perspective on the lives of people with learning disabilities over the last century. After reading this chapter, one will have a better grasp of why British people with learning disabilities have been so dangerously disconnected from primary healthcare services, and why there has been until now little pressure on these services to adapt to accommodate their needs. Persaud’s chapter is followed by Todd’s deeply thoughtful sociological analysis of the connection between death and learning disability — the consequence of which is that ‘the deaths of people with learning disabilities appear to be deaths that have been too readily overlooked and infrequently discussed’. This will not be the case for any longer due to Todd’s unique contribution.

Furniss’ chapter roots us back into the lived experience of people with learning disabilities who are dying and maps out for us the professional networks that are necessary to engage if we are to come close to approximating a ‘good death’ for those in our care. With the luxury of time or forethought, Furniss demonstrates that this is an entirely achievable goal.

The issues of palliative pain and symptom control are often very complex and none potentially more so than in the care of people with learning disabilities who may have multiple co-morbidities, complex pre-existing drug regimes and communication difficulties. The chapter by Regnard *et al* is therefore vital reading. The wisdom of this chapter is borne out of joint working across the disciplines of palliative care and learning disability. Its gift to this book is the establishment of the idea that such complex needs can be assessed (by baseline recording) and addressed in a proactive way, which reduces distress and thereby enables other non-physical needs to be explored and a reasonable quality of life to be achieved right to the end.

The learning-disability nurse may well be the person who has known the patient consistently over many years; however, this is a role that is not well-understood in primary health care and especially within secondary care such as specialist palliative care. Persaud’s chapter is therefore very useful in making clear the unique contribution that this professional can make to the dying

person with a learning disability, and again borne out of years of experience it has much to teach us.

Increasingly, the decision-making processes of the medical profession are coming under intense scrutiny. The pendulum has swung far from seeing the doctor as ‘the expert’ to seeing him or her as but one of a number of professionals, each with their own unique expertise and valid opinions. This may well be the case and it is an important tension to hold given the very real power which historically the medical profession has held in the lives of people with learning disabilities. That being said, the stringent ethical underpinning of medical training makes doctors uniquely suited to navigating the moral maze that often surrounds the learning-disabled person at the end of their lives. Unless one has direct experience of palliative care, it may not be at first obvious that such thorny dilemmas are everyday — the arguments over whether or not to treat, and quality over quantity of life.

Read’s chapters on communication and counselling will facilitate the adaptation of practice for the psychosocial professionals within the palliative-care team. Amazingly, their dying, if dealt with sensitively, may be the opportunity for the person with learning disabilities to deal with a number of unresolved issues. Read’s practice-based wisdom makes this more likely.

Perhaps one of the most neglected areas of care for people with learning disabilities is that of spiritual care. Swinton’s chapter highlights some of the reasons why this is the case, and why many religious institutions have been either unwelcoming or severely limited in their understanding of the person with a learning disability’s ability to express both spiritual need and spiritual competence. At the end of life, for many, spiritual issues and questions of ultimate meaning become of prime importance. There is no reason for us to suspect that this should be any different for the learning-disabled person. Swinton’s chapter enables us to reflect on these issues and equips us to begin working on both facilitating and meeting these needs.

McEnhill’s chapter takes a look at the development of the modern hospice movement and its neglect of people with learning disabilities within it. However, its value-base means that the adaptation need not be as huge as one at first may think. The keys elements of listening to the individual and of working in a multidisciplinary team are explored. It is the individual whose story is told here — and who has the wisdom to offer, rather than the institution itself.

The final chapter is given over to the topic of research in palliative care and learning disability. This is of vital importance given the dearth of reliable information that we have on these topics currently. Lindop’s chapter enables us to think through the sensitivities related to ethical research in this area and also points to areas that require further attention. It is a fitting close to a book that, hopefully, will spur practitioners and academics on to think new thoughts and test them out for the benefit of people with learning disabilities at the end of their lives.

It has been said that statistics are ‘people with the tears removed’. This could also be said of many academic books, no matter what their area of focus. However, it cannot be said of this book. Not only does this book contribute a wealth of new knowledge, but it does so by interspersing the theoretical thinking — which is vitally important — with casework and the wisdom of seasoned practitioners. Much more importantly, it does so by projecting the voices of those whose experience teaches us much about our frailty as practitioners, but also about the importance of striving to try, tentatively, to get it, if not right, then better. My wish is that we are able to hear clearly and succinctly within its pages the echoes of these learning-disabled people who have so willingly shared their wisdom at the end of their lives, and that we might learn from them and become ‘good enough’ carers for those who follow them.

Linda S McEnhill  
Coordinator NNPCPLD  
December 2005



## PREFACE

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This book is probably the first of many textbooks that will focus on the potential issues involved when learning disability and palliative care combine to produce complex situations in the palliative-care context. It will be an important text, and will help to raise the profile of this neglected area. I intended to generate a text that was informative, easily accessible, interesting and useful to the range of professionals involved in delivering and providing palliative care to people with learning disabilities. It may not contain all the solutions to the complex dilemmas involved, but it does highlight the potential challenges we face and offer strategies to support and promote good palliative-care practice for this client population.

Dr Sue Read  
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December 2005







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My grateful thanks to my friends and colleagues, who have expressed interest, shared the challenges and offered unconditional support throughout this journey. To Robin and Chris, who both patiently put up with many hours of me being sequestered away in my study — thank you for your tolerance and understanding.

I would particularly like to thank my fellow contributors for their time and effort in contributing to this book. These experts in the field are all very busy people, who all care passionately about their respective interests. It has been a fascinating, tiring, exciting and adventurous journey.

Finally, this book is dedicated to all those people with learning disabilities who have let us into their lives and taught us so much about life's most painful lesson: death and dying. The lessons, sadly, continue.

Dr Sue Read





# Historical perspectives — care for people with learning disabilities over the past century

*Michelle Persaud*

Care for people with learning disabilities has changed beyond recognition over the past century. It is essential to our understanding of the present, and indeed the future, to look back at the delivery of health services for people with learning disabilities, and to examine the principles on which their care was based. This chapter gives an overview of how people were cared for from 1913 in large hospitals; the effect of institutionalisation on them; and how they were viewed by society as a whole. It will address the effect of this transition from institutional hospital care to community-based services on their ability to access the services that others take for granted, particularly palliative-care services. It will also address the impact of the new theories that changed the way we perceive groups that society regards as ‘different’, thereby shedding light on the ways in which people with learning disabilities became marginalised.

## Overview

In the late 1960s, there were roughly 60,000 people with learning disabilities living in hospitals in the UK, and many more living in the community (Lindsey, 1998: 71). Government policy began to concentrate on moving these people away from long-stay institutions to community provisions. The 1972 White Paper *Better Services for the Mentally Handicapped* recognised the negative impact of institutionalisation and segregation on people’s lives, and that people with learning disabilities didn’t necessarily require an institutional-care environment. This resulted in a national move to re-house people in ‘ordinary’ communities with the ambitious target of reducing the number of beds to 5000 by 1997.

In that year, New Labour continued the policy of the previous Conservative government by maintaining the programme of closing down long-stay institutions. They also acknowledged, as had many others in the field, that ‘the move from large institutions to small size accommodation does not automatically ensure that the type of care provided will be any less “institutional”’ (Brown and Smith, 1992: xvi). In the hope of addressing the inequalities faced by learning-disabled

people, the Government published *Signposts for Success* (Lindsey, 1998), which turned out to be a landmark document, detailing good practice for commissioners and providers of healthcare services for people with learning disabilities. The main theme of the document is captured in the opening words: ‘the National Health Service was founded on the principle that good quality health services should be available to all’ (Boateng in Lindsey, 1998: 1).

As social-policy directives continue the decommissioning of large institutions, people with learning disabilities are using community services more than ever before. This includes health services that will be required to take a full part in maintaining the health of individuals who may have greater needs than most. This is especially true of the last people to move from large institutions, as they tend to have the most complex health needs (Hayward and Kerr, 1998).

Good quality lies in the nature and scope of services available — and quality of care is paramount in the delivery of services to people with learning disabilities. It is difficult, however, to measure quality of care when the person being cared for is unable to speak for themselves, and when services have changed so drastically over the past two decades. The changes are both political and social: political, in the shift of emphasis for health care to be provided within an internal market; social, in the sense of policy development embracing a philosophy of human services that are provided within the community. Critics of the move away from hospitals would argue that the agenda, far from being a humanitarian one, was more cynically grounded in fiscal policy, rather than social or health policy. Current service provision for people with learning disabilities looks very different now to the way it did in the 1960s, when the ideas and principles of a theory called ‘normalisation’ were just emerging in the UK healthcare system.

In 1913, the Mental Deficiency Act was introduced. It prescribed paternalistic care and, more importantly, protection for people who had acquired the label ‘mentally defective’. It established a ‘Board of Control’ that was directly responsible to the House of Commons via the Home Secretary. The Board was in the powerful position of ‘assisting to breed out the hereditary transmission of mental defect by preventing the propagation of a degenerate stock’ (Potts and Fido, 1991: 140). The Act defined four main categories of defect:

- **Idiots** — persons unable to guard themselves against common physical dangers.
- **Imbeciles** — persons whose mental defectiveness does not amount to idiocy, but who are incapable of managing themselves or, in the case of children, could not be taught to do so.
- **Feeble minded** — persons whose mental defectiveness does not amount to imbecility but who are in need of care, supervision and control for their own protection, or, in the case of children, could not benefit from instruction within a school.
- **Moral defectives** — persons whose mental defectiveness is coupled with strong vicious or criminal propensities that need controlling for the protection of others.

Fuelled by the calls of people such as Mary Denny in the 1890s that children classified as ‘mentally defective’ should be ‘detained for the whole of their lives as the only way to stem the great evil tide of feeble-mindedness in our country’, there was demand for the creation of new public institutions culminating in two thousand such places being available by 1914 (Potts and Fido, 1991: 10).

Life in these institutions (or ‘colonies’, as they were also known) was grim. Rules and regulations were strictly designed to ensure the smooth and efficient running of the institution: ‘[they] did not allow for individual self-expression, nor did they permit some basic human rights.



The institution controlled everything, including contact with parents, relatives and the world outside' (Potts and Fido, 1991: 57). It is no wonder that society came to accept the fate of learning-disabled people as being one of segregation and hospitalisation. Locked away from mainstream life, these people rapidly came to be seen as 'deviant' or 'subnormal'. 'You never went out for anything because [they] did everything in the hospital' (Cooper, 1997: 24), 'everything' including all health care and treatment. Life was confined to the institution. Health care and health screening amounted to a very cursory examination on admission by a consultant psychiatrist. He (the doctors tended to be male) would check the ears and chest. The usual type of entry to records would be 'chest field appears clear. No obvious illness or infestation'. This 'examination' would be repeated annually with the resulting record entries stating 'remains the same' (Beacock, 2001: 56). As late as 1980, there were still nurses training for the title 'Registered Nurse – Mental Subnormality', and the care was provided within a medical, paternalistic context.

In the 1970s, a new theory emerged, which was to become internationally influential in human services: 'normalisation' (Flynn and Nitsch, 1980: 3). As with any new theory, it generated much debate and gained as many critics as exponents. Even now, the debate is far from finished, although it is universally accepted that the theory is built on the principles of quality of life and services. Bank-Mikkelsen (1969), who was head of the Danish Mental Retardation Service, was instrumental in having the concept of normalisation written into Danish law in 1959. He postulated that normalisation should mean 'letting the mentally retarded obtain an existence as close to the normal as possible' (Wolfensberger, 1980: 75). This marked the beginning of the normalisation debate in an international context (even though it still belonged primarily to 'mental retardation' [learning disability] services). In a keynote address to a 1977 conference of rehabilitation educators, Wolfensburger discussed, in a general way, the 'role that service agencies play in the twin and opposed processes of deviancy, devaluation and normalisation' (Flynn and Nitsch, 1980: 4).

Whereas Wolfensberger applies these principles universally for all 'deviant people', Bengt Nirje (1969) described normalisation in relation to mental retardation services. Although Wolfensberger is often seen as the 'father' of normalisation by some, and as the person who finally took the concept and illuminated it by others, all three authors — Bank-Mikkelsen, Wolfensberger and Bengt Nirje — are what commentators would call 'classical definers' of 'normalisation', and all deserve recognition.

## **What is 'normalisation'?**

Since Wolfensberger introduced it into North America in the late 1960s, the theory of normalisation has evolved into a systematic and guiding principle for the design and delivery of services for all 'devalued' people, but mainly people who are learning-disabled. Wolfensberger's version has had the most impact in the UK than its predecessors. He writes:

*Normalisation implies as much as possible the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people.*

Wolfensberger and Tullman (1989: 29)

It is assumed from this principle that human services therefore have a major role in the improvement of people's valued roles, and in defending them if devalued.

Critics of normalisation are keen to point out that even if the principles are based on providing 'normalised' services, interpretations vary. Some professionals incorrectly assume that normalisation means that the person, as opposed to the service, is to be 'normalised' (whatever that may mean). But normalisation is 'not something that is done to a person. It is a principle for designing and delivering the services a person needs' (O'Brien, 1981: 26). Conversely, Walker and Walker (1998) assert that this is one of the main arguments against the philosophy (as they call it). They state that even with 'normal' provision, there could be inadequacies and inappropriateness for varying service users. What becomes clear is that any philosophy, principle or concept is always subject to misinterpretation, whatever its author's intention.

Highly conscious of this, Wolfensberger, in his later work, discarded 'normalisation' in favour of 'social role valorisation', and in his book about the subject introduced the concept as being born out of normalisation. He called it a 'high-order concept for structuring human services' (Wolfensberger, 1992: 1). Like Goffman before him, he understood that the social identity of people who were 'mentally retarded' (learning-disabled) was 'stigmatised' and that these people were (and, arguably, still are) given a different or lesser service or existence compared with the 'normal' or 'ordinary' person.

Goffman (1963: 11) identified the person who was stigmatised as being someone who was different. The stigma isn't necessarily a physical sign on the body but something 'applied more to disgrace itself than to the bodily evidence of it'. He says that, collectively, humans have rules and norms of behaviour that are acceptable: something he calls 'social intercourse'. When we are alike and in the presence of each other (he argues), these rules, which govern social intercourse, help us anticipate others. However, when a stranger arrives, we tend to assess his or her social identity (rather than social status) by appearances. The implication for people with learning disabilities is profound, especially when there are also physical attributes that vary from the 'norm'.

Bogdan *et al* (1982) argue that human beings transmit stereotypes and characteristics of devalued or deviant people largely through what is called 'the unconscious association of social symbols or images'. There are abundant examples of these images in popular culture: one need think only of, say, Captain Hook or Frankenstein's monster.

Wolfensberger (1992: 11) has suggested that society uses negative social roles to identify a devalued person as:

- Other — ie. alien, different.
- Non-human — seen as human once but no longer: ie. a senile or comatose person.
- Menace — object of menace or dread, or threatening in nature.
- Object of ridicule — the butt of jokes or amusement.
- Object of pity — afflicted, felt sorry for.
- Burden of charity — society has a duty of care but only at the most basic subsistence level.
- Child — two forms: the eternal child who never matured to competent adult; and the adult who is having a 'second childhood' — a person with dementia, for instance.
- Diseased organism — the person in the role of the sick or diseased organism requiring therapy or treatment, usually dispensed by medical personnel in medical surroundings (hospitals, clinics).

Particularly pertinent in the field of learning disability are the last two categories, which, arguably, are the way many people with learning disabilities are still viewed, consciously or subconsciously, even in the twenty-first century.

In 1999, the Department of Health (DoH) carried out a review of the quality of services for people with learning disabilities, which resulted in a report entitled *Facing the Facts* (DoH, 1999a). It exposed many deficiencies in health and social care for people with learning disabilities. Concurrently, the DoH completed a review of the Mental Health Act (1983), which concluded that subjecting people with learning disabilities to the provisions of the Act is wholly inappropriate. It also conceded that a citizen should only be subject to the authority of the legislation if he or she is suffering from a defined mental illness. Beacock (2001) argued that the Act is grounded in paternalism and protection, and that it is still used inappropriately in today's practice. Until new legislation is passed, in the form of a new Mental Health Act, people with a learning disability are still subject to being detained as being 'impaired', even in the absence of a defined mental illness. Because of the nature of learning disability, and the devalued social identity often ascribed to people who have it, helping learning-disabled people find or create valued roles (or enhance the valued roles they already have) becomes essential. Their right to equality of social opportunities and healthcare services is as strong as anybody else's.

Many studies about the health needs of people with learning disabilities show similar findings. Some specific conditions are more prevalent amongst this population than amongst the general population (Kerr *et al.*, 1996). Identification and diagnosis of conditions and illnesses can be problematic because of difficulties in communication and understanding. Coupled with the fact that government health policy has traditionally excluded learning-disabled people from mainstream services, we now face a huge challenge in equipping services to meet the needs of these previously excluded people. This challenge falls into two halves: changing the culture and attitudes of providers; and giving services with the education and training needed to deal with learning-disabled people.

## **Cultural and attitudinal change**

Beacock (2001: 62) asserts that people with learning disabilities have 'too little political influence to challenge the bastions of modern society and too small a voice to be heard above the clamour and din of competing interests at the healthcare table'. He develops this assertion by stating that when caring for people with learning disabilities and their health needs, 'it is not simply about health and illness; it is about valuing people who are not the same as you'. A policy of segregation has only exacerbated the negative perception and treatment of people with learning disabilities by society and, arguably, health services too.

Within a National Health Service that is already overstretched, there are many demands for resources and money. Attitudinal change also demands resources and money. It also takes time: it is a long and sometimes arduous process throughout systems that have been developed around institutional processes and routines, not necessarily people. Given that people with learning disabilities have the same illnesses as everyone else, but may also have communication and cognitive difficulties, these systems are challenged to help the person achieve the same health

outcomes. Wilson and Haire (1990) describe the fact that health systems are 'reactive', meaning the individual needs to seek help in the first instance.

Before they even seek help, however, they must first be able to recognise that there is a problem. Kerr (1998), citing Kinnell (1987), asserts that because of communication difficulties, there will be under-reporting of symptoms of physical and mental illness within the learning-disabled population. Beacock (2001) agrees, arguing that mental illness, in particular, is under-reported. He goes on to claim that not only does lack of communication exacerbate under-reporting in this group, but also that the ability of carers and professionals to recognise symptoms needs to improve. He suggests that carers, both formal and informal, 'may well be inclined to interpret and treat behaviours, rather than symptoms'.

Matthews (2002) suggests that at the first interface of health service delivery, primary care, there is little knowledge about the needs of people with learning disabilities and how their health is compromised. He also suggests that there is an unrealistic expectation on the part of specialist services (learning disability) that primary care teams should provide health screening and surveillance for learning-disabled people. This would be in contrast to people in the rest of the population, who self-present and take responsibility for their own healthcare needs. What he argues is that specialist learning disability services (when given the appropriate training and tools to do the job) are highly effective in screening and surveillance, and that the outcomes for people with learning disability are significantly improved as a result. Tuffrey-Winje (2002), cited in Jones (2003), agrees, but strikes a cautionary note by pointing out that the timing of engagement of specialist services (palliative care, diabetes clinics, etc) is crucial, or people with learning disabilities may suffer delayed identification of life-threatening illnesses because of difficulties in diagnosis.

The challenge for change will undoubtedly be tested in the audit of health services, particularly primary care. Each strategic health authority must be able to prove the numbers of people with learning disabilities accessing services. This will require GPs routinely to record this information. Statistical data will indicate uptake rates for screening and surveillance services, but qualitative research will need to be carried out to identify how well services are achieving better healthcare outcomes for people with learning disabilities. One explicit policy directive from *Valuing People: a New Strategy for Learning Disability for the 21st Century* (DoH, 2001) is that every individual will have a health action plan. A person called a 'health facilitator' has a crucial role in developing this plan in partnership with the individual and primary health services. These plans are evolving documents that should reflect changes in the lifestyle and health needs of the individual, as necessary. The Government (via the Valuing People Support Team) has a responsibility to ensure that the targets are met within this policy initiative. Only audit will show if the rhetoric has been matched by reality.

## **Education and training**

There is much work to do in this area. Education about the health needs of people with learning disabilities is required by the individuals themselves, by carers and by professionals in specialist and generic health services.