CREATIVE ENGAGEMENT in PALLIATIVE CARE

new perspectives on user involvement

EDITED BY LUCINDA JARRETT

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Contents

*Paula Clarke's contribution to this book is included as a result of her wishes prior to her death and of her partner's recent agreement.

Dedicated to Paul Laking

And the many palliative care service users I have met over the past ten years who have showed me how to live a better life.

Thanks to all those who have contributed to the development of user involvement in palliative care, and in particular to Michele Angelo Petrone.

Foreword

How things began

Once upon a time, there was a very clear idea of what should happen if someone had a problem, or they were ill and wanted some kind of help. Because governments had been made to realise that life could be very hard for people if they didn't have much money, the state in Britain had set up its own services that anyone could use. This included schools and housing; money if you were sick, pensions, help with children and so on. But people were most proud of and talked most about the health services that the government set up. The idea was that everyone should have the best healthcare available and it would be free 'at the point of delivery'. Of course, even before that, for a very long time, people in great need could get help from churches and charities, although there wasn't always enough to go round. Also if you had lots of money, you could go and buy what you wanted and wouldn't have to go anywhere near officials.

However, as people began to get used to the services provided by the government and forgot what it had been like before, they began to think more carefully about what they were like. They realised that although they were often very good services, they weren't always quite what they wanted (especially if they came from minority communities), it was sometimes difficult and took a long time to get them and the quality was not always quite the best. They also noticed other things. They noticed that people who worked in these services, even when they were excellent, sometimes didn't seem to realise how important it could feel to be treated as though you had a mind of your own and that you might have opinions and views of your own. You wanted to know things and play an active part in what happened to you.

Wanting to make a difference

People talked about feeling that health services could put you in a passive position. They talked about 'paternalistic' services; that is services which were there to do 'good for you', but didn't really involve you actively in the process.

And then people started to talk about *getting involved*. They began to wonder if services, like health and care services, really could be the best, if patients and service users didn't have any say or control over them. 'They say they know best, but I know myself better than they can'. 'Ok they have been trained and read the books, but what I know, I know from direct experience. That is important too.'

This book is about user involvement. It is concerned with sharing knowledge and experience about user involvement in palliative care and making it more real for the future. But two other issues are central to it. First, is its commitment to an imaginative

approach to user involvement. Second, is the way that it highlights that while people who use palliative care services face particular difficulties and barriers, this is no reason why they cannot be involved if they wish to. Some commentators have highlighted the ethical and practical problems around involving palliative care service users. People may have limited time. They may well be very ill, tired and facing discomfort. All these issues are true, but they should never be advanced as reasons why people who want to cannot be involved. They are also a key reason why imaginative and supportive approaches to user involvement, which this book highlights, are so important here.

There is one more issue to remember. In modern times, the importance of 'end of life care' was highlighted by the pioneers of the voluntary hospice movement. They emphasised the importance of palliative care being based on an holistic approach that took account of all aspects of people's lives and deaths; medical, social, spiritual and material. More recently the work of the independent hospice movement has been complemented by the development and expansion of specialist palliative care in state provision. This is another reason why it is now so important to take forward user involvement energetically, so that regardless of which sector people receive support from, they can expect equal opportunities in terms of their views and voices being listened to.

It is helpful to be clearer about what user involvement can mean. It is a complex idea and there is little agreement about its meaning. It can mean many things. It can be a process, a value, a means and an end. It can have very formal and structured expressions. It can also be something that we do so routinely, that we don't even realise we are doing it!

We wrote an initial statement about user involvement for this book to help contributors and we are incorporating it here. But there are no absolutes in this field. As you will see a little later, the one thing that people most associate with 'good' user involvement is that it leads to positive change in line with what they want. That is a light we should never lose sight of, but much else about user involvement is still the subject of lively discussion.

What is user involvement?

It is not an easy exercise to define user involvement. Other terms are also used as well, like patient and public involvement, consumer and citizen involvement and participation. There is no agreement about what service user involvement or these other terms mean.

However, there are some common themes which seem to be associated with user involvement.

User involvement is about more than filling in 'satisfaction' surveys/questionnaires. It is not just about being a passive 'data source'. It is a more active process, involving people in speaking for and acting for themselves. It is associated with other terms like empowerment and partnership.

People can be involved in all sorts of ways. User involvement often means being consulted or being asked to be members of formal groups and bodies with a focus on user involvement. Some people feel that 'consultation' doesn't really count as user involvement, because it can be so limited. People worry about 'tokenism'.

User involvement however can mean much more. This includes receiving a budget which you control; active consultation (where there is a commitment to listen to your views) It can mean being able to contribute your experience, ideas and views in all sorts of ways. It can take many different expressions. It need not be based on conventional meetings and letter writing. All sorts of ideas have been developed, from having a party

to work out what you want to do, creating poster displays, organising meet and greet sessions, to running your own workshop or event.

It can be something that people do as individuals and as groups. User involvement can take all kinds of forms, from people getting together to set up their own independent 'user controlled' organisations' (seen by many service users as the most important expression of user involvement), to one off events, conferences (which they run), gatherings, performance, poetry, arts, cultural activities. User involvement can be fun, as well as a serious business. What defines it is that the purpose is for people to have opportunities to speak for themselves and for their perspectives to be respected and acted on. Good user involvement respects difference, addresses diversity and seeks to be as inclusive as possible. This means, for example, ensuring that people can take part if they have physical or sensory impairments, learning difficulties, experience of mental distress or do not communicate verbally or speak English, or where English is not their first language.

The most valued kinds of user involvement are where involvement leads to change in line with service users' rights and needs; where people are directly involved in decision making and have some financial control. In a nutshell good user involvement is involvement which makes a difference and can lead to discernible change and improvement in people's lives. It is about enabling service users to be involved as part of a process of development and change in line with what they would like to see, recognising that different interests also have to be negotiated.

User involvement can be related to all sorts of activities, including training professionals, planning and managing services, inspection and service monitoring, defining quality standards, research and evaluation, producing learning materials, staff recruitment and promotion and in shaping, developing and assessing workers' practice.

User involvement activities can include support and mutual aid dimensions as well as being concerned with sharing views and making change. These two dimensions can often be blurred and overlap as service users seek to gain confidence and capacity to participate on more equal terms.

All these issues crop up in this book. This book brings together a wide range of exciting experiences in this field. It shows just how much has been achieved in a very short time. In our view, user involvement has come relatively late to palliative care, perhaps because of the anxieties professionals have had about the capacity of service users to be involved without damaging personal cost. This is time for celebration of achievements so far. But there is still a long way to go and hopefully this book and its contributions will help many more in palliative care, both practitioners and service users to take forward this life enhancing enterprise.

A participatory process

There is one last point that needs to be made here. This book has itself had to address issues of user involvement in its own development. Its production has been a participatory process. People with many different backgrounds and experience have contributed to it. It includes accounts from a range of different perspectives. Some of the people whose contributions are offered here are not used to writing and certainly don't have experience of writing professionally. For some people English is not their first language.

One of the aims in producing this book has been to make it possible for people to contribute their ideas and perspectives regardless of conventional familiarity and exper-

tise with writing. The aim has been to offer support wherever necessary to enable people to offer their unique perspectives and accounts of their experience.

This means that there are many different perspectives in this book and they are offered as people have wanted to offer them. Contributions have been put together in different ways and while the aim has been to produce an accessible and readable book, no attempt has been made to homogenise people's styles or to impose one standard narrative on them. This would defeat the object of the book, contradict its commitment to participation and ignore the complex ethical and philosophical issues involved.

Instead the goal has been to respect the process of producing people's contribution as they prefer, trying to be transparent about how this was achieved. Where people have been supported to make their voices heard, this involvement has not been denied, but equally supporters have not put themselves or their views into the picture unnecessarily. The aim has been to enable people to be able to 'do it their way' with a real sense of control and to be able to communicate their unique words, voices and experience. This is and will always be a key potential of user involvement.

Suzy Croft and Peter Beresford
August 2007

Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is also Chair of Shaping Our Lives: the national user network. Shaping Our Lives is an independent user controlled organisation which is funded by the Department of Health to increase user involvement at local and national levels in health and social care and raise the standard of services and support service users receive. Peter Beresford is also a Visiting Fellow at the School of Social Work and Psychosocial Studies at the University of East Anglia. He is a long-term user of mental health services and active in the mental health service users/survivors movement. He is also a Trustee of the Social Care Institute for Excellence.

Suzy Croft is a senior social worker at St John's Palliative Care Centre and Research Fellow at the Centre for Citizen Participation at Brunel University. She is a trustee of two leading UK palliative care organisations and she is a member of the editorial collective of *Critical Social Policy*.

Preface

In 1996 I set up a project called Life Stories. The aim of this was to enable people to find ways to tell stories. I had been working at the BBC for three years in science documentary production where I loved meeting people and encouraging them to tell their stories but found it hard to reconcile the intensity and conviction of each individual story with the need to make it fit into a science narrative that was owned by a director/producer and copyrighted by the production house. I wanted to find a place to work where people could own the stories they told.

I began working with a movement therapist, Filipa Pereira Stubbs and we spent several months exploring ways of using movement to enable people to find ways of accessing the stories that were important to them and their families. When we approached hospices with the idea of enabling people using their service to tell their own stories for themselves, the idea was much welcomed. 'The user's voice' was at the heart of our approach and this was immediately recognised by palliative care services. The voice of the service user has always been significant in healthcare. The celebration of that voice is particularly significant for the most vulnerable and frail service users, people who are living with life threatening and long-term illnesses. For many patients, chronic illness means long-term dependence on disability benefits and the process of qualifying for this can be demoralising and psychologically debilitating. For patients who are facing death, the process of disappearing from a cultural arena is one of increasing powerlessness. Finding voice enables people to choose whether to regain a role in their social and cultural arena. This choice begins with the active engagement in communication between patient and family and between patient and healthcare providers.

A London hospice user who could not communicate her despair welcomed the chance to write a poem that contained it and communicated it directly to her social workers or counsellors. Her emotions were held by the form of the poem and the form itself gives clarity to complex emotions. A mother with young children who worried that her voice would be lost as her children grew up without her welcomed the chance to make a video that left a lasting legacy of her daily life with her family through her illness. She was able to offer her children her voice when she worried that they would be left with nothing.

The creative arts clearly have a large role to play in enabling people to find a shape to hold their individual stories. This personal creativity also has a public and political role in enabling people to choose whether or not to get more involved in the places where they receive care. The arts make an effective public statement. If a person is able to display their artwork on a hospice/hospital wall it enables him/her to hold some ownership of that space. The artist becomes a stakeholder in the institution because their artwork is displayed. Similarly a performance/film screening/poetry reading enables someone to

take ownership of an event in the place where they receive their care and in so doing feel more responsible for what takes place in that space.

At a personal level, families who may feel that they cannot cope with the management of the disease that is overtaking the person they love may manage to take control of their daily lives by becoming involved in a creative project. Sorting out the photos, editing a manuscript, viewing rough cuts of a film quickly becomes a family process and in this way carers are more able to get more involved in aspects of the management of the lives of those who are seriously ill.

Some individuals may want to get involved in public campaigning and in addressing the issues that face people who are living with serious illnesses. Maxine Edgington worked with Billy Bragg and Rosetta Life to create a song entitled 'We Laughed'. This was released as a single into the UK Charts and reached Number 11 in October 2005. Maxine welcomed the chance to speak about palliative care, the issues facing single mothers living with illnesses and embraced the opportunity to challenge the stereotype of the passive victim of suffering, replacing this with the positive image of a celebratory love song. She became involved in changing the representation of the dying. Others choose to become involved in education and the delivery of medical care. Groups have been set up to enable patients to talk to doctors and explore with them specific training issues – communication, understanding pain, addressing emotions, for example.

The links between finding voice and becoming involved in the delivery of care are not necessarily direct, but there are clear paths between them. An artist activist like Michele Angelo Petrone who has made a lifetime's commitment to placing the emotions of the patient at the forefront of the agenda of doctor-patient communications has chosen to make his art a statement of soul pain and has made public the need to making soul pain present in healthcare institutions by curating exhibitions in hospitals and hospices across the country. However, most people living with a life threatening illness are concerned to keep themselves and their families as stable and safe as possible and use their art to restore their self-esteem on a personal level.

The process of finding voice is significant in giving people the confidence to express themselves to family, healthcare workers, friends and colleagues. It can be quite distinct from 'user involvement'. However, if a politicised and active collective users voice is to make a significant contribution towards the delivery of healthcare, it could be the first step towards enabling people to take choices about how they want to become involved. As Suzy Croft and Peter Beresford argue in the foreword, 'user involvement' may mean many different things. It does not necessarily mean attending users forums or filling in questionnaires about the delivery of care in a day centre.

This book outlines the role that the arts can play in enabling people to make choices about how they would like to take ownership of their identity, their lives they lead with illness and the places where they receive care. *Creative Engagement in Palliative Care: new perspectives on user involvement* invites us to be bold and imaginative about how we take forward ideas about user involvement and how we not only build on the successes of the past but also offer new ways forward for the future of people living with life threatening illnesses.

This book sets out to explore how people can find their voice; it looks at some of the opportunities available for people to use their voice through examples that others have offered; it looks at the links between personal creativity and public identity and the role the arts, public education and medical education play in delivering change. It is clear that art is transformational. The role of metaphor – which often lies at the heart of art – is to

show things in another way, to transform our seeing of objects, experience, the world. In the context of life threatening illnesses, the arts enable people to find their voice to express their identity and to encourage a wider audience to see people differently.

The book is divided into four parts, Finding a voice, Developing support, Advancing involvement and Models of good practice that offer practical guides for people who would like to implement some ideas into their own practice. The first part is dedicated to the development of individual narratives. Chapter 2 contains the narratives of three people who were all at St Lukes Hospice in Basildon in 2003: an artist, a service user and a doctor. The three people demonstrate the different languages we negotiate when trying to find our voice – the medical narrative of care, the creative language of cultural debate and the personal voice of each individual. Some of the narratives are the isolated voices of strong service users. A single patient may choose to develop their work and with increased confidence make a powerful statement, as Katherine Vaughan-Williams made with her work, 'A Guide to Living with Cancer According to PG Wodehouse', reprinted here in full in Chapter 3. This was a text that was developed in the hospice and performed in public at Hampstead Theatre, July 2003. In making a public statement she was able to make clear her own reflections about living with cancer.

Maxine Edgington's song celebrated her love for her daughter. Maxine wanted to make a public statement about love of a mother for her daughter and after the song had been produced wanted to celebrate the impact of the song on her life. Her song made a clear statement about the ability of people facing death to celebrate life and remain active in their community. The process of making the song is described in Chapter 6.

It is also important to recognise that finding voice is not only about standing up and speaking. The most important step is the first step taken and this is often the gesture of inviting someone to listen. The first step into a hospice. The first session with an art worker. Overcoming frailty and fear is complex and in Chapter 5 I outline ways of using non-verbal communication – movement and dance – to overcome fear and to accept support. This process relies on a transformation in the audience and the listener. We have to learn to listen to frailty and to reach out and support the performer. We have to learn to connect. We need to be open to different forms of art to enable people to perform themselves safely. Support is essential and the second part of the book is dedicated to Developing support.

Working with support groups is a well-established way to build structures for user involvement. Developing users groups and users forums has been very successful in mental healthcare where mental health service users have become active stakeholders in their places of care. In several mental health day centres service users not only sit actively on trustee boards but are also involved in the operational management of the centre. At Chelsea and Westminster Hospital, mental health service users have been active in recruitment and often sit on recruitment boards for new members of staff, including consultants and psychiatrists.

However, in chronic illness, terminal illness and life threatening conditions the role of service users is more complex. While a mental health diagnosis is often a lifelong condition, it is not always life threatening. People have a lifelong investment in the delivery of the service. A life threatening diagnosis is distinct. People either face a terminal diagnosis at the end of their life where frailty, and debility make active and useful functioning on trustee boards not necessarily effective, or people experience a life threatening diagnosis and recover after surgical intervention (HIV/AIDS, breast cancer, prostate cancer, for example). In these instances the most effective support can be collective

through the formation of user groups that enable people to express feelings with safety. As is effectively pointed out in Chapter 9, support groups are not so much about activism for change as enabling people to find a safe space to be themselves without being judged. Support groups offer the safety of a confidential space without judgement. Some people may find voice within a support group and then want to make a public statement to deliver change. The work of Francesca Beard with a group of women who attended St Johns Hospice outlined in the second part of Chapter 10 pays tribute to this process and the group of women she worked with performed their work live on stage at Riverside Studios in 2004 and then they went on to collaborate with Francesca Beard in the writing of a play for broadcast on BBC Radio. A collective voice is an effective vehicle for strategic change. It enables a representative group to make clear public statements. However, it is important to realise that while a collective voice is useful for effective delivery of change, users forums, users groups are not always appropriate sites for activism. Support is not always synonymous with confidence and is not necessarily part of the development of a clear sense of personal or political identity.

The strategic bridge between finding identity, developing support and advancing involvement is not straightforward. In Chapter 7 Nuala Cullen and David Alcock explore some of the complex ideas that finding voice and identity pose to an individual hospice and look at the challenges St Andrew's Hospice faced when adopting the ideas and principles of good creative practice and of user involvement. At its most simple the role of personal storytelling has a direct impact on the new developments of narrative based medicine. Narrative is important in medicine because it performs a 'bridging' function that enables doctors (and other healthcare professionals) to travel across this bridge, taking the patient's story of illness and repackaging it in the form of a case history. It is important to involve the patient in this process and allow the story to travel to and fro in conversation so that the patient's story is kept alive. In principle, this means that a healthcare professional needs to allow the patient the time to tell their story. Sometimes people become trapped within their story of illness. Attentive listening enables a doctor to offer a different story to enable a patient, who sees themselves as passive victim, to become transformed, to see themselves as active participant in their narrative, changing the words that the doctor has given and finding their own language and their own story. The development of narrative based medicine is a good example of how doctors and patients can collaborate in the development of simple strategies to build bridges between finding voice and user involvement. If the doctor can give the patient enough time to tell the story and find their voice, the patient becomes an active participant in the delivery of their care. In this way, both doctor and patient educate each other and teach each other how to communicate.

In Chapter 12 doctors Emma Hall and Jennifer Todd outline ways in which patients have been involved in the training of medical students. This offers a clear way forward for the development of the art of storytelling within conventional medicine. These users groups are dependent upon the confident voice of the service user and sufficient support networks.

In Chapter 13 Sue Eckstein outlines a drama project that began with a group at St Christopher's and explores some of the ethical issues that surround how the group contributed to the final public piece of writing. This group is one where growing support and compatibility are the outcome of a creative group and where a confident support group contributed to the public voice. This development of public art shifts the practice from within the fabric of healthcare to public art. In this realm the art has a clear activist agenda.

The ethics of ownership and copyright become complex when an artist takes responsibility for the development of a work out of a collective process. These ethics still need debating in public and within traditional healthcare if the confident voice of the service user is to remain at the forefront of the agenda. Politically, it gives people the courage to voice themselves and it is important that the voice of the artist is one of collaborator and not interpreter if this political activism is to develop a significant voice in our culture.

One of the most significant developments is the potential of the internet to offer a creative and unmediated voice for service users. Julian Stallabrass has outlined the democratic principles of internet art and these principles remain intact despite international censorship laws. The MS Society website offers message board forums where service users can explore issues from new diagnosis to everyday living, and message board forums targeted to young people, carers as well as people living with MS. In Chapter 14 we look at current online strategies to enable people to communicate their voices and ideas and the implications of the internet and new technologies for developing user support and involvement strategies. The last part of the book looks at models of good practice. Poems for World Day was an online initiative that invited service users and staff from across the world to submit poetry for an anthology published on World Day. The initiative was designed to find the voices of the national and international community and support this voice through the forum provided by the website. Chapter 16 is a bold look at how to use service user forums to challenge the culture of gratiude within the hoospice movement and the last chapter of the book pays tribute to the views, stories and direct experiences of the members of the Help the Hospices service user involvement initiative.

First and foremost, the book is intended to be a good read. A survey of how people are tackling these ideas and some of the measures being introduced. It is dedicated to Paul Laking, a very good friend. In 1999 I stayed in his family home in Suffolk while running a residency at St Nicholas Hospice, Bury St Edmunds and was welcomed into his home and family. He became involved in the stories that I was listening to and came to the celebration event that marked the end of the residency. A couple of years later he became involved in a short video drama we produced in collaboration with bereaved teenagers, where he played the father to the lead character. Three years later he was diagnosed with secondary cancer in his liver and died several weeks later. I lent him a video camera he used to record stories for his family and also suggested he wrote some poems and explored his own lyricism. He emailed them to me and they preface each section of the book. His final text was sent to my phone a week before he died. He was watching fireworks over the Suffolk coast and was amazed at the brilliance of the fireworks and the intensity of his experience of life as he faced death. He loved life and had an incredible curiosity that enabled him to get involved in almost everything that intrigued him. His poems invite you to listen and understand his perspective of living with a terminal illness. I hope you will be inspired by this and the other stories you read and be encouraged to get involved yourself.

Lucinda Jarrett
August 2007

About the editor

Lucinda Jarrett is artistic director of Rosetta Life, an artist-led organisation that delivers artist-led residencies in hospices and hospitals across England. She founded the organisation in 1997 in order to challenge our contemporary representation of illness and to enable people who are facing death to participate more fully in cultural life.

Lucinda read English Literature and Theatre at Edinburgh University and then studied the semiotics of dance at the University of Paris. She worked in television for five years where she worked as assistant television producer for French, American and British broadcasters, and has written and performed performance poetry across London venues. She is a published writer and has worked with independent dance venues and independent dancers and has a strong track record of delivering theatre within healthcare settings.

List of contributors

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Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is also Chair of Shaping Our Lives: the national user network. He is a long-term user of mental health services and active in the mental health service users/survivors movement.

Chapter 1
Chris Rawlence is a film maker, writer and librettist. Since 2001 he has been working with Rosetta Life where he is an artist in residence at Greenwich and Bexley Cottage Hospice.

Chapter 2
Heidi Morstang is an artist specialising in photography and the moving image.

Dr Elizabeth Shafford has worked in child health and paediatrics with 20 years' experience in the field of paediatric oncology. She now works part time at St Luke's Hospice, Basildon.

Margarita was a service user of St Luke's Hospice, Basildon.

Chapter 3
Katherine Vaughan-Williams was an influential architectural historian and writer. She adored 1960s radio comedy and PG Wodehouse who inspired this work. Katherine died in September 2003.

Chapter 4
Marielle Macleman studied drawing and painting at Duncan of Jordanstone College of Art and Design, Dundee and now co-ordinates the arts project at the Prince and Princess of Wales Hospice, Glasgow.

John Lieser was diagnosed with cancer in 1999 and given a prognosis of weeks. He was referred to the Prince and Princess of Wales Hospice, Glasgow where he is an active service user.

Chapter 5
Lucinda Jarrett is an artist who works with words, moving images and performance.

Miranda Tufnell has been working as a dancer and choreographer since 1976. She has also trained in Alexander Technique and craniosacral therapy.

Chapter 6
Billy Bragg, is an English musician renowned for his blend of folk, punk-rock and protest music. He has been active for over 20 years.

Maxine Edgington was a service user at Trimar Hospice, Weymouth. She died in March 2006.

Catherine Batten is Rosetta Life artist in residence at Trimar Hospice, Weymouth. She also works with West Dorset Food and Land Trust where she co-ordinates the Bridport Local Food Heritage Project.

Chapter 7
Nuala Cullen is the Principal Family Support Worker at St Andrew's Hospice, Grimsby.

David Alcock is the Creative Therapy Co-ordinator at St Andrew's Hospice, Grimsby.

Chapter 8
Gillian Chowns is a Senior Lecturer in Palliative Care at Oxford Brookes University and a former Specialist Palliative Care Social Worker with the East Berks Macmillan Palliative Care Team.

Sue Bussey is a Specialist Palliative Care Social Worker with the East Berks Macmillan Palliative Care Team.

Alison Jones is a former Principal Social Worker with Thames Hospice Care and was instrumental in setting up their Bereavement Service. She is a qualified counsellor and since her retirement has worked as a supervisor and trainer for Cruse Bereavement Care.

Nick Lunch has been an enthusiastic advocate and pioneer of participatory video (PV) techniques for 10 years and is Director of Insight (www.insightshare.org).

Chapter 9
The women who use the St Thomas's Hospital support group are living with breast cancer or need support as a result of breast cancer treatment.

Chapter 10
Suzy Croft and the St John's Hospice Women's Support Group and Francesca Beard.

Chapter 11
Phil Cotterall is a Research Fellow in Palliative Care at Worthing and Southlands Hospitals NHS Trust.

Chapter 12
Dr Emma Hall is Consultant in Palliative Medicine, St Christopher's Hospice, London.

Dr Jennifer Todd is Consultant in Palliative Medicine, Trinity Hospice, London.

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Bobbie Farsides has been teaching and researching in the field of bioethics for almost 20 years. In July 2006 she moved to a new post at the Brighton and Sussex Medical School where she holds the Foundation Chair in Clinical and Biomedical Ethics.

Chapter 14 and 15
Lucinda Jarett is an artist who works with words, moving images and performances.

Chapter 16
Judith Hodgson is the Senior Lecturer in Psychosocial and Education Services at Dove House Hospice, the Vice Chair of the Association of Palliative Care Social Workers and a Trustee of Help the Hospices.

Chapter 17
Suzy Croft, Peter Beresford, Munir Lanani, Di Cowdrey, Mandy Paine, Karen Willman, David Hart and **Anne Macfarlane**: Help the Hospices' User Involvement Initiative.

PART 1: **FINDING A VOICE**

My Place at the Front of the Queue

I know my place
I'm the one without the luggage
The big adventure at the front of my view.
Sure of my place in the queue.
Looking back at people
Things we've done
Excited by the prospects
New experiences or none
Part of the biosphere or a golden plover on Ixworth water meadow?
Can't look at that now.
Got to look to make sure they they know
Where the spare wheel is
How to make bread
How to change records on the jukebox
Who to call when the computer plays silly buggers
All not-mes doing my job
Love-you-and-leave-you
Hugs a little longer
Kisses nearer to on the lips
Looks full of meaning
'How could you go, you bastard?'
'How could you? How could you?'
When you gotta go, you gotta go, babe
Journey to the Indies
Sail off into the sunset
On red tsunamis.
Beauty and Death.
Love and rockets.

Paul Laking
1 January 2005