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Lastly we wish to acknowledge the following journals in which passages of the text have previously appeared: Psychologists Special Interest Group in Elderly People (PSIGE) newsletter, Changes, Journal of Dementia Care, Mental Health Journal, Elderly Care and Signpost.
How much should the authors of a book know about the subject matter before setting out to write it? The idea of writing a book certainly could imply that it already exists somewhere, and only awaits transformation into physical reality. Perhaps it is so with some. This book has certainly not been like that. In many ways the process of bringing it into being has paralleled the experience of undertaking communication work with people with dementia, where it seems that the thoughts and ideas emerge only in the very process of talking and writing about them.

Our collaboration has taken the form of a series of extended and searching explorations of John’s experiences. By the time we agreed to write the book together, he had spent five years working as a writer in residence with people with dementia. It had become clear to him early on in that period that important things were happening for people during the course of the work. It emerged only much later that important things were also happening to John. The next few years were spent (not exclusively) on a process of reflection on the nature, meaning and implications of the work. Prior to this John had proceeded largely intuitively, guided by a strong set of values, and developing new awareness and skills as he went, but not subjecting his experiences to conscious analysis.

Kate brought to this process a fascination with the subject, and a deep regard for the experience of the person with dementia. In keeping with her training
2 Introduction

and experience in psychology, she embarked on trying to achieve an understanding of what was actually going on in this kind of communication and relationship.

John endured a lot of cross-questioning in the course of our collaboration on this book. For example:

- Why did you do that?
- What did she do then?
- How did you feel about it?
- What do you think an observer would have made of that?
- Would you do the same now?
- What do you think that means?
- How does that fit with what we think we already know?

It was often only while engaged in this process that we began to apprehend the complexity and subtlety of what had been going on, and there was a real sense of excitement in starting to give shape and expression to it. We hope that at least some of the quality of our enthusiasm comes across in the writing. Sometimes the sheer intricacy and shadowiness of what we have been exploring has felt daunting, even overwhelming. It seems that we are raising a whole lot of difficult and complicated subjects and then trying to string them all together into a coherent whole.

There are lots of maybes in the book. We really understand so little about dementia: what it is, how it affects people, and what are the best ways of thinking about it and responding to them. Quite often we found ourselves in the position of describing a set of circumstances, and then speculating on how they might be understood or interpreted. From here we have further speculated on the implications, and soon it feels as if we are sitting atop a set of interconnected limbs and we may wonder how we got there. Since we are all so early in the process of getting to grips with the meaning of dementia, we feel an attitude of tentativeness and openness should be the norm. You may find much that you disagree with us about, but if we have raised issues, prompted questions, excited curiosity and sometimes aroused passions then we will have achieved some success.

It will quickly become obvious that in the course of developing our argument we use a great many quotations – not only from people with dementia, but also from other writers in the dementia world and elsewhere – fiction, poetry and other areas of study. Our justification of this strategy is threefold: first, it is so often the case that another writer has made a point much more eloquently than we could ourselves; second (and this applies only if we have used their words fairly) the fact that someone else has said it reinforces our argument; and third, we believe strongly in the value of drawing on the thinking and experience of writers outwith the field of dementia care. It would also be fair to point out that sometimes finding the passage came first, and this then prompted us to develop a particular line of thinking. In this way we hope the book will be strengthened by its links with other subject areas and disciplines.

Throughout the book we have quoted extensively from the words of people
with dementia in their conversations with John. In accordance with the principle of confidentiality we have done everything we can to seek permission to use these, from the individuals themselves, and often from their relatives as well. In all the texts names, places and certain other details have been changed in order to preserve anonymity. In addition to this, all of our chapter titles embody quotes from people with dementia. We have a very strong sense of responsibility in representing people’s thoughts here, not only in terms of passing on messages which people clearly wanted others to be aware of, but also in protecting people who are in a vulnerable situation. It has been done in a spirit of respect, humility and the hope that their words and actions, which are so often powerful and vivid demonstrations of people’s continued integrity and struggle, will help to improve the care of people with dementia everywhere. We therefore earnestly hope that no one will be offended or upset to recognize their words or those of a relative or friend. The book would be immeasurably the less without them, and its chances of making a difference much reduced.

We should briefly explain about the terminology we have used. Regarding the name of the condition itself, we refer to it simply as ‘dementia’. We are aware in so doing that we are implying that there is just one thing called dementia, which of course is not true. However, it would quickly become unwieldy always to refer in the plural to what is probably a group of conditions which have features in common. We also wish to avoid referring to ‘the dementias’, which carries unfortunate overtones of people themselves being referred to as ‘dementias’. We do not use the word ‘disease’ or ‘illness’ since this implies that dementia is purely a medical entity. Rather the more neutral term ‘condition’ is used, which being vaguer is more inclusive of the psychological and social aspects alongside the physical ones.

As regards talking about the person themselves, we reject the term ‘sufferer’, which is still the most common way of referring to the individual with the condition. It is too negative in tone, but even worse it defines the person entirely in terms of their having dementia. Instead we have used the phrase ‘person with dementia’ or ‘people with dementia’, and while this may be clumsy at times, it seems the clearest and most value-free description. We never describe a person as ‘demented’ since this again defines them in terms of the condition, and also implies that they have reached a qualitatively different state, perhaps even some kind of endpoint. (We should acknowledge that the terms ‘sufferer’ and ‘demented’ are used in some of the quotes employed.)

Since most of John’s experience has been in nursing homes, much of the material quoted or discussed arises from that context. We appreciate, however, that there exists a great diversity in terms of the services used by people with dementia, including, increasingly, home-based support. Similarly most of his work has been with older people, though of course dementia affects people in their forties and fifties too. Whilst many of the issues raised will be common to both groups, some will differ.1

Although the material is complex we have tried to make the book as easy to use as possible. It is in five parts. The text is framed by two portraits, in their own words, of Alice and Jane, both of whom have dementia. The idea here is
to present these individuals directly to the reader, to set the person with dementia centre stage. Alice raises all sorts of questions which we hope the book will go on to address, and Jane invites us to reflect on her words in the light of what has gone before.

In between come a series of chapters which can be broadly grouped into theoretical, practical and thematic categories. After the words of Alice, and a chapter on the idea of personhood in dementia, which provides the context and sets out the fundamental ideas and values of the book, Part 1 continues with material on the basics of communication. The four chapters in Part 2 constitute a guided tour of practical aspects of an interaction. The three chapters in Part 3 deal with larger themes which seem to have special significance. There could have been many more of these, but selectivity was necessary. Part 4 concentrates on implications of what has gone before for care practice, and also the ethical dimensions of the work. Because both of these subjects are all pervasive, we have given each a special role in the book. Sections on implications for care and ethical implications therefore appear at the end of most chapters.

**Our starting points**

We do not see ourselves as presenting a theory of dementia, nor indeed a theory of communication. We have not attempted to review the ideas of others. There is other work which does this, and it would simply have made this book too long. When relevant to our argument, however, we do refer to other authors and recommend work by them. But, of course, despite the lack of a coherent theory our arguments are based on a set of assumptions. Instead of delineating these, however, we have decided to identify some of the common beliefs about dementia which this book is setting out to challenge:

- that dementia is primarily a physical condition which leads to predictable deterioration in the person’s cognitive, social and practical skills
- that what makes a human being a person is lost somewhere in the development of the condition
- that the ability to communicate, both verbally and nonverbally, is located within the individual, and steadily declines as the condition progresses
- that the individual has no meaningful inner life or awareness of what is happening to them
- that dementia undermines the need and capacity to maintain relationships or form new ones
- that all aspects of memory steadily deteriorate until the individual’s existence is entirely unsupported by it
- that the individual progressively loses emotional coherence and control
- that dementia leads to a decline in all creative disposition and expression
- that other people are helpless to influence the progress of the condition, and that the result is always an experience of loss.
Part 1: Basics
1 Conversations with Alice: ‘A far fetch’

Alice lives in a mental health unit in a nursing home in England. She is a short, dumpy woman in her mid-eighties. She has a shock of silverying hair, black bushy eyebrows and rather protruding blue eyes. Most of her days are spent walking around the unit attempting to engage other residents in conversations; her attitude in these exchanges is usually one of haughty impatience. Occasionally she sings ‘Hee haw, hee haw’ in raucous tones over and over in a manner which seems calculated to annoy. At other times she sleeps. There are days when she is too ill to talk at all.

Often, however, she appears deliberately to seek out John in order to unburden herself of ideas and feelings that she has been saving up. They have had over twenty extended conversations of this kind spread over as many weeks. His role is that of a befriender and listener as well as recorder, not that of a carer or clinician. His knowledge of her illness is minimal. He responds to her as a person. Their friendship is based on mutual trust. One day she says to him:

Anything you can tell people about how things are for me is important.

But at times she gets impatient with the process they are undertaking together. After working with John one day, and getting angry and upset with herself, she shouts to a member of staff:

Take this man away! I don’t want to fill in any more of his questionnaires.
Underlying it all, however, there seems to be a sense of urgency in what she is doing. She says things like:

You’re only coming in the nick of time. A lot of this has already faded.

Mostly she seems desperately to want to recall her life and times, and she approaches the task with positive resolve:

I don’t think I’m going to forget this again. No, I think I’m going to manage it. Sort it out without a doubt.

At the same time she remembers that what she is embarked upon is, for her, a process fraught with difficulties:

It’s a far fetch this writing of my life.

There is scope for humour and playfulness, however:

I must tell you the tale of my life, sir, but I don’t want my tea to get cold.

This latter statement seems to carry a special significance when directed at John, which it has been on more than one occasion. She also enjoys saying things like:

Daniel in the Lion’s Den

has slipped away by hissen.

These rhymes when occurring in the middle of prose conversations partake of the same enigmatic quality as many of her other utterances.

There are occasions when she realizes that willing the process cannot bring results:

I have the idea that too much fussing about memory makes it worse.

and:

It’s so foolish to get yourself in a knot. Or to grieve about getting yourself into a knot.

Some memories come from very early in her life:

I had a younger sister, and when my mother asked her ‘Do you remember father?’ she said ‘No, was he the poorly man in the bed?’

They may only last a few moments, or a sentence or two, as in:

I can hear my mother singing in the kitchen.

Sometimes a sense of fragmentation seems to be uppermost. The thought that everything is slipping away from her is very upsetting:

It’s the terrific confusion of things that worries me more than anything else.

There appears to be an element of doubt about her own identity, as in:
This isn't my voice today. I've not heard myself sounding like this before. It isn't my cough either. It's a tomfool cough. And it belongs to Tom.

But despite this, she has a great need to try to make sense of what is happening to her:

I don't know why I came here. But I think it was for my health. You see, we know the Cause but cannot cope with the Effect.

She knows that she is not well, and perhaps believes that her problems might be hereditary:

I never expected to be in this silly condition. My grandmother would say quite frequently 'I do forget.' And now it has come to me.

Sometimes she rationalizes it, as in:

It's as the Lord made it that I have forgotten so many things. Just think if you carried all that around with you all your life!

Alice also speaks of her sense of loss regarding her intellectual powers:

The brilliance of my brain has slipped away when I wasn’t looking.

And she gives expression to her need to understand what is going on:

After all, what is this lump of matter if you can't make sense of it?

She talks about her surroundings in a rather indirect way, as if she cannot bring herself to admit it is her own situation to which she is referring:

That's the Nursing Home over there, isn't it? Well I hope never to be there.

and:

There are lots of cars rolling up to that Nursing Home. Oh, I hope I don’t have to go into one of those places.

She comments on features of the environment and the people in it:

The set-up here is very complicated. You have them howling around the place thinking it's straight forrard.

And:

We seem to be having rather a fussy do. The yowling has been enough to scare anyone's wits.

She appears to use an extended metaphor to talk about her experience of living in the home:

I'm suffering from monkey-puzzle. The monkey-puzzle is this place. The puzzle is: how do I cope with the monkeys?

Clearly the monkeys are despised authority figures, and they are linked to the 'peppering':
Well I've had my mouth nicely peppered this morning, not literally you understand. ‘Peppering’ appears to refer to being talked about behind one's back.

She has plenty to say on what seems to be the subject of her relationships with other residents:

The kids have told me straight. ‘We don’t like you.’ I didn’t like being told. But it’s honest - I’m really pleased to know.

Sometimes Alice talks of being detained against her will:

As you well know I’m a prisoner here. My sister has stolen my life. Now I’m old and expected to dream my time away.

She seems to need to have a wider perspective on her situation:

I want a natural life where I can see my forebears and enjoy the fruits of my labours.

and:

I want to get to the point where it’s a matter of course.

Alice’s emotions range from the bleakest despair:

I’ll end up dotty, I’m afraid they’ll break me up for firewood. I’m good for nothing else.

to elation:

Oh, you know, we are cared for, aren’t we? People try so hard to get us into a normal situation. It comes over me in a distinct feeling of joy.

Ultimately she seems aware of the power differential between herself and those who are in charge, and makes a rather stunning request of John:

Are you a person who could swing it for me with the authorities? I want you to ask them a question for me.

Would they please give me back my personality?

The purpose of this brief chapter has been to present a portrait of Alice in what were her current circumstances and state of mind as far as possible in her own words. The interpretations we have offered are provisional and subjective. Her style of speaking and the things she said were both absolutely distinctive and memorable, and also shared characteristics with those of other people John went on to meet, some of whom are quoted later in this book.

The last words must be Alice’s own. This is a complete piece she dictated to John on his last visit. It illustrates many of the characteristics to which we have drawn attention. She responded to his questions about the phrasing she wanted. But once the text was finalized she showed no interest in either hearing it or viewing it.
I can’t remember anything of today except the peppering of my tongue. Yes, my mouth was peppered again this morning. As an educated man, I thought perhaps you might be an expert in these matters. I believe it is all part of the monkey-puzzle.

These little monkeys have two legs, you know, and wear suits. These whiskers that are growing around the lower part of my face, I did think that they formed part of the category of the monkey-puzzle, just put there to irritate the newcomers. But what can’t be cured must be endured. You wish the trouble was at Timbuktu, but if it can’t be then it has to be here.

I’ve come to the conclusion that we should educate these monkeys. First of all, I should make it perfectly clear to them that there are certain things that are not done, even though I know that they are laughing their heads off behind my back.

This man who has just entered the room, is he to be trusted? Could he be one of the monkeys? No, I don’t think so, he hasn’t got the brain. But he doesn’t seem very interested in us. Each morning he has his little sport. It doesn’t involve me. Each day I watch it as an observer. I am thinking it might be a source of the peppering that is going on.

My sister definitely said to me ‘Don’t let them get you!’ Talk about a monkey puzzle! Well I reckon they got me!’

If you said to me right now ‘Would you like to give a present day outline of your life?’ I wouldn’t know. I’m here. I’m comfortable. But who put me here I wouldn’t know. I never intended to be here. Yet it’s familiar enough. And here’s me whining away like some silly petted baby. Surely I must have been kidnapped to end up here long past my bedtime?