

Media Release

Telling Tales about Dementia: Experiences of Caring

Edited by Lucy Whitman

Published by Jessica Kingsley Publishers ISBN: 978 1 84310 941 9

In this unique anthology, thirty carers from a variety of backgrounds describe their experiences of looking after a partner, parent or friend with dementia.

‘Caring for someone with dementia is a lonely and bewildering experience,’ says **Lucy Whitman**, who edited the anthology. ‘My whole family was profoundly affected when my mother developed vascular dementia, and we struggled on without much support. My hope is that others who are caring for someone with dementia, who read this collection, will feel less isolated, and more able to continue to cope.’

These ‘**Telling Tales**’ will have you laughing one moment, crying the next. They document harrowing instances of neglect and indifference, prejudice and incompetence, but also demonstrate the resilience, resourcefulness and enduring love of so many people who are endeavouring to maintain the best quality of life they can for their families in the face of grief and adversity.

Marylyn Duncan, from North London, describes the neglect her mother Camilla suffered in the local hospital. The nurses would leave food out of reach of frail patients who were unable to feed themselves, and Marylyn’s mother developed pressure sores on her heels, which were left untreated for weeks, ‘to the point where my mum, in her wisdom, said that mice were gnawing at her heels.’

Peggy Fray, 85, from Lytham St Anne’s in Lancashire, cared for her sister, Kathleen, who had Down’s Syndrome, for 40 years. Kathleen developed dementia in her 60s, and suffered greatly in her final years. Despite many government recommendations for changes to services to help those with learning disabilities who develop dementia, Peggy says: ‘Sadly people with learning disabilities are still being put in the wrong places – into care homes where they suffer because of lack of staff training and understanding.’

Jim Swift from Bolton is caring for his wife Jan, who was diagnosed with dementia at the age of 58. ‘Jan was a head teacher in two schools, and taught hundreds of children to read, write and compute,’ says Jim. ‘Now, she cannot do these things herself. Even after six years, I wake up devastated by this illness that has blighted our lives.’ But Jim says he is determined ‘to make every day golden’ for his beloved wife.

In compiling the anthology, Lucy worked closely with the charity **for dementia**. Lucy and many of the other contributors are members of the charity’s carers’ network, **Uniting Carers for dementia**, and many have benefited from the services of **Admiral Nurses**, (specialist nurses who support families affected by dementia) who are trained and supported by **for dementia**.

John Suchet, Patron of **for dementia** and carer of his wife Bonnie who has dementia says of **Telling Tales**: ‘The single most valuable achievement of this book is to tell carers they are not alone. The more of us there are, the stronger we become, and the better we can fight for our loved ones in the face of this cruel disease.’

Copies of 'Telling Tales' are available to purchase direct from **for dementia** at £12.99 (including post & packing), raising £6.50 per copy for the charity to help expand the charity's services. Log on to www.fordementia.org.uk for details or call 020 7874 7203.

ENDS/ Notes follow

Notes

The mission of **for dementia** is to improve the quality of life of people affected by dementia by promoting and developing **Admiral Nursing**, providing high quality **training** and promoting best practice for professionals working with older people, carers and people with dementia, and supporting the carers network **Uniting Carers for dementia**. Professional and family carers and people with dementia can call the dedicated **Admiral Nursing DIRECT** phone line 0845 257 9406 on Tuesdays and Thursdays 11 am- 9pm, leave a message at any other time for a call back, or email questions to direct@fordementia.org.uk. For more charity information log on to www.fordementia.org.uk.

for dementia's charity launch of 'Telling Tales' Tuesday 20 October
St Anne's Soho, Dean Street, London W1D 6AF
4 – 6pm, refreshments at start and end of the event.

Programme:

- 4pm Refreshments
- 4.30pm **Welcome by Barbara Stephens, Chief Executive, for dementia**
Lucy Whitman: Editor and Contributor
Diana Melly: wife and carer of jazz legend George Melly who died with dementia
Graham Stokes: a view for health and social care professionals
Readings from *Telling Tales* by Peggy Fray, Marylyn Duncan and Jim Swift
John Suchet - personal response to the book and the readings
Barbara Stephens - conclusion
- 5.15-6pm Refreshments

Please register if you wish to attend by emailing info@minervaprc.com

Future events

Readings from the book with different contributors will be held in and around London between October 2009 to February 2010, and at events outside London throughout 2010.

To receive further information about these events please email fundraising@fordementia.org.uk