



LIFE STORY WORK WITH PEOPLE WITH DEMENTIA

Ordinary Lives,
Extraordinary People

Edited by Polly Kaiser and Ruth Eley
Forewords by Tommy and Joyce Dunne

‘This book really manages to capture the multi-layered and multi-faceted nature of life story work. It sets life stories within the bigger frameworks of health, psychology, policy, culture change, identity, equality and diversity. We hear about life stories from many people living with dementia, families and professionals covering care at home, care homes, housing, hospitals, end of life, memory assessment services and arts venues. It ranges from the practical to the existential and fizzes with case studies, top tips, and research evidence.’

– *Professor Dawn Brooker, Association for Dementia Studies,
University of Worcester*

‘Life stories, a strand in psychological therapy with older people and people with dementia, has been unfolding over the past 25 years. This timely book brings the many facets of this work together.

Here is a sparkling treasure trove of a book containing all you might want to know about life story work and dementia. Written with clarity and in an accessible style suitable for lay persons, it also contains all professionals might want to inform their practice and develop services that place the person with their unique life story at the centre.’

– *Reinhard Guss, Chair, Dementia Workstream Lead, Faculty of the Psychology
of Older People, BPS, Consultant Clinical Psychologist, KMPT*

‘This is a really good and useful contribution. It is full of well-curated information and practical advice, but above all it is full of the humanity of people with dementia and the value of their stories. I thoroughly recommend this book.’

– *Sube Banerjee, Professor of Dementia, Centre for Dementia
Studies, Brighton and Sussex Medical School*

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Foreword

As a person living with dementia, I can't stress enough the importance of life stories and involving the person with dementia in creating their own life story. After all, the best perspective for understanding behaviour is from the internal reference of the individual themselves.

Every day we lose another piece of our life that will be gone forever unless our family, friends and carers are able to reinforce those memories by going through our life story –whether it is a book, photo album or memory box – with us over and over again. Without this, people will never know the person behind the dementia. In a care home or hospital we would just be a resident or patient with *Dementia* instead of a *Person* with dementia.

They say that knowledge is power, so what better way to have the knowledge to be able to communicate with a person with dementia than to find out what was important to them in terms of their memories, experiences, life events, values and beliefs.

It's vital that people know about what type of food I like, whether I'm a vegan/vegetarian, what my religious beliefs are, did I like pets, did I play sports, what school I went to and my employment history. The life story should contain such details as the name I liked to be called by, whether I was married, names of children and grandchildren, parents and friends, as well as my employment experiences and hobbies.

We can take away a lot of stress for people who will be caring for us by detailing our wishes regarding health and financial matters, so why not detail our life story to enable people to have empathy with us.

Care homes would benefit from life stories as they allow staff to enter into the world of the person with dementia. They can go through the book each day with the person and learn about their life, their likes and dislikes. They can help add to the book because it is an ongoing work in process.

It's a great experience for a person with dementia to sit with someone over time to make a personal record of important experiences, people, places and events in their life and provide a way of communicating with them (and their family carers) about their life.

I personally hope that my own life story will give people an insight into the person I was and the person that I now am. But I urge my peers and everyone else to start their own life story today because you never know what the future will bring.

Tommy Dunne

As Tommy's wife – and now his carer – I do worry that I may not always be there to look after him, but through having his life story book I know that people will be able to get to know him and see all that he has achieved.

A life story book epitomises a person's life and can help achieve person-centred and relationship-centred care tailored to meet individual needs. It assists care-planning and helps ensure that the person receives the best possible type of care for their wellbeing. As life stories draw on residual long-term memory, they can provide a medium for communication that promotes self-esteem and wellbeing – vital to help prevent isolation.

Having a life story book is a great way of communicating, because if you 'know' about the person you will be more relaxed and that is something that the person will pick up on. Having the book helps to make the person feel proud, valued and appreciated.

Sometimes a person with dementia does not recognise their spouse, children or friends, because in their memory that person is living at an earlier time and should look much younger. Using photos of an earlier time will often help their recognition of family and friends.

A life story book can be a great distraction, and distraction is what all good carers must master to help the person maintain their happiness. It also safeguards personal identity and can increase carers' understanding of confused or agitated behaviour.

The book can help care home staff to appreciate the person with dementia in the context of their whole life. It should help them understand the person better and change negative views and assumptions about the person.

The tools in this book will help you make a great life story.

Joyce Dunne

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Polly Kaiser and Ruth Eley