Who cares?

Information and support for the carers of confused people

Health Promotion England
Who cares?

INFORMATION AND

SUPPORT FOR THE CARERS

OF CONFUSED PEOPLE
# Acknowledgements

Original edition researched and written by Maggie Jee and Liz Reason. With grateful thanks to the steering committee and the carers’ support groups, whose experience and advice form the basis of this booklet. This edition has been developed with the valuable assistance of Help the Aged, Age Concern (England) and the Alzheimer’s Society to whom Health Promotion England extends its grateful thanks.

Whilst every effort has been made to ensure that details in this publication are up to date, changes in the benefits system and in social services mean that some facts may be incorrect. You are advised to check either with your local Citizens Advice Bureau or one of the other agencies listed on p.76.

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INTRODUCTION

If you are reading this booklet because some of the comments on the cover struck a chord with you, you may be looking after someone who has dementia.

This booklet has been written to tell you:
- more about dementia
- what it is like for someone at home
- how to ease the problems of day-to-day care, and
- about the help available to carers.

Dementia is a distressing condition and a lot of what follows in this booklet may be painful to you. But the booklet is not primarily about dementia. It is designed to support you, the carer. It has been written with the advice of many people who are or have been carers themselves and who have shared their experiences to help others. All the examples and quotes used in the booklet are based on what different carers have said. After reading the booklet, you may want to discuss what you have read with your doctor or with a counsellor who is familiar with the condition.

It is hoped that these carers’ experiences will support you in a task that may at times seem daunting and thankless and help you realise that you are not alone. Wherever possible the booklet is optimistic — not because everything will be easy, it won’t — but because many carers have stressed that whatever the difficulties, there are also small triumphs to be won.

ABOUT DEMENTIA

Dementia is a complex and perplexing condition. It includes a number of different diseases, of which Alzheimer’s disease is the most common. As a carer you need good information and support to help you understand the condition and its consequences.
WHAT IS DEMENTIA?

Dementia is a condition in which the cells of the brain die more quickly than in normal ageing. This leads to a general decline in a person's abilities. It can produce loss of memory, confusion, odd behaviour and personality changes. The causes are not yet understood. There is no cure for dementia, and little treatment can be offered, although new drugs are beginning to be developed that alleviate some of the symptoms of Alzheimer's disease. Since the same symptoms may result from other disorders, which may be curable, it is important to get a proper diagnosis. Dementia by itself is not usually a cause of death and someone may have the condition for several years before dying from something else.

There are two main types of dementia. Their symptoms and effects are much the same although they progress differently.

- In Alzheimer's disease changes take place in the structure of the brain, leading to cell death. The onset of the disease is gradual and the decline usually slow and regular.

- The second main type of dementia happens when 'mini' strokes take place in the brain which destroy small areas of cells. This is called 'multi-infarct' (or sometimes vascular) dementia. It often progresses in a step-like way and the onset may be sudden.

The person may not get any worse for periods of time, and may even seem to improve, although decline will be the eventual outcome. Some people have both Alzheimer's disease and multi-infarct dementia together.

Other types of dementia include Lewy body disease, Pick's disease, Parkinson's disease, Huntington's disease and Creutzfeldt-Jakob Disease (CJD).

WHO WILL GET DEMENTIA?

Dementia is usually a disease of old age, with six in a hundred people over the age of 65 developing it to some degree, increasing to twenty in a hundred among people over 85. However, it is estimated that as many as 17,000 people under the age of 65 have dementia and hence have particular and specific needs that are not necessarily dealt with in this book. Please contact the Alzheimer's Society for more information.

As far as is known, dementia occurs equally across all groups in society. Unlike many other diseases it does not appear to be linked with social class, ethnic group or geographical location.

WHAT CAUSES DEMENTIA?

Because dementia is such a distressing illness and is not fully understood you may have anxieties about the nature of the disease, especially about its causes and your own chances of getting it.