Who cares?

INFORMATION AND SUPPORT FOR THE CARERS OF PEOPLE WITH DEMENTIA
ACKNOWLEDGEMENTS

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Please note that there may be changes in the benefits system and in social services after publication of this booklet, so you are advised to check benefits and services issues with either your local Citizens Advice Bureau or one of the other agencies listed on pp.89–91.
INTRODUCTION

If you are reading this booklet because some of the comments on the back 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.
- 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 this booklet are based on what different carers have said. After reading the booklet, you may want to discuss what you have read with someone who is familiar with the condition, such as a doctor or one of the agencies listed on pp.99–91.

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 anything will be easy, it won’t – but because many carers have stressed that whatever the difficulties there are also small triumphs to be won.
WHAT IS DEMENTIA?

The term ‘dementia’ is used to describe the symptoms that occur when the brain is affected by specific conditions, including Alzheimer’s disease, stroke and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding.

Different areas of the brain are responsible for different skills and abilities. The changes in behaviours, memory and thought in people with Alzheimer’s disease may be a direct result of the way the disease has affected their brain. The causes are not yet understood. There is no cure for dementia, and little treatment can be offered, although new drugs have been developed that may for some people temporarily 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 most common 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 ‘vascular’ dementia. It often progresses in a step-wise 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 vascular dementia together.

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

WHO WILL GET DEMENTIA?

Dementia is usually a disease of older age, with six in 100 people over 65 years of age developing it to some degree, increasing to 20 in 100 among people over 85 years. However, it is estimated that as many as 18,500 people under the age of 65 have dementia. Younger people with dementia have particular and specific needs that are not necessarily dealt with in this book. Please contact the Alzheimer’s Society for more information.