

Care Homes

THE ONE - STOP GUIDE

June Andrews is an international dementia specialist adviser, and Professor Emeritus in Dementia Studies. During her decade directing the University of Stirling's Dementia Services Development Centre, she co-wrote *10 Helpful Hints for Carers*, a book on helping care for those with dementia, which has sold over 65,000 copies. She has received a Fellowship of the Royal College of Nursing (RCN), the highest honour awarded to nurses in the UK, and in 2016 she was awarded an OBE. She advises families, organisations and governments across the world. She is also author of *Dementia: The One-Stop Guide*.

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ALSO BY JUNE ANDREWS

Dementia: The One-Stop Guide: Updated Edition
(Souvenir Press, 2020)

10 Helpful Hints for Carers
(with Allan House, University of Stirling, 2009)

When Someone You Know Has Dementia
(Greystone Books, 2016)

Dementia: What You Need to Know
(Profile Books, International Edition, 2016)

Demencja: Kompleksowy przewodnik po chorobie
(Harmonia Universalis, 2015)

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When, Why and How
to Choose a Care Home

June Andrews

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Introduction

Who needs this book? Over 100,000 people who have to make this choice every year in the UK.

When is the right time to read this book? You need it badly if you are in the middle of a crisis that will lead to searching for a care home. However, I hope that some people will read it long before then, to understand what might be in store and how to make the best of things. This includes other things you need to plan ahead, like setting up powers of attorney so that someone can make decisions for you, if you can't do that yourself. And financial planning, so that receiving care doesn't completely wipe out any legacy you intended to pass on to the next generation.

Not least, reading about it in advance means that you can set yourself up so that care or a care home (if, or when, it is needed) is a joy and a respite, exactly as you would want it to be, and a welcome solace when living independently has become too hard or lonely. We might not like to contemplate it, but with half a million of us in care homes at any one time, the chance that you or someone you love or care for will need this is very high. If you're prepared, you can make the best of it, and in many cases the resident can have a really good time, with kind, caring and knowledgeable friends. A good care home is a reward for a life well spent, and providing that care is a joy for the people who do it well. You want to avoid the pitfalls.

Choosing a care home is one of the more emotional and expensive decisions that anyone ever has to make. You make a commitment that amounts to tens of thousands of pounds and that will continue for an unpredictable time, maybe for years. It may never have crossed your mind to prepare for it. You may not have previously discussed what everyone involved – including the person going into the home – would like to happen, if such a day comes. You are probably doing this without experience, under time pressure and in an emotional whirlwind, while adjusting to illness or loss of capacity in a loved one. You might be reeling from the death of one parent, while having to decide how to care for the other. You may have difficulty getting other family members to agree to your choices, and feel judged by others – neighbours and friends, and even the relative you are supporting – for what you eventually decide to do. Sometimes you even promised that you would never allow it to happen, but circumstances are now against you.

Even if the care is funded by a local authority, you may bear the responsibility for choosing the location, and your choice can lead to you subsidising the local authority with top-up payments, in an attempt to improve on the bare minimum that the state has provided.

There are almost 500,000 care-home beds in the UK. Each one is occupied by a person who has either chosen it themselves or had it chosen for them. The majority of residents (up to 90 per cent) are frail older women who have dementia. There are exceptions, for example some younger people with dementia, men, people with learning difficulties or brain damage, and a wide range of vulnerable adults and children. The majority of people making the choice for another are oldest daughters or other relatives of the person moving in. In other cases the choice is made by social workers, or even the person themselves. People

rarely take up places in a care home as a lifestyle choice. The cost can be prohibitive.

For the majority – those with dementia – there is the added complication of legal mental capacity, meaning that a court order may be needed to make decisions, if they did not set up a power of attorney in advance to allow someone else, chosen by them, to make decisions on their behalf. It all means trouble and expense. A judgement has to be made, balancing the advantages and disadvantages of care at home or in a care home.

The length of stay of frail older people in care homes is reducing. From choice or cost containment, the date of entering a care home is now closer to the end of life than it was previously. This faster turnover of residents means that increasing numbers of people make a care-home choice every year. If you are reading this book, you may be among the thousands looking for advice about how to make this decision. My hope is that you will find the information you are looking for here.

I have worked in care homes and been involved in the management of care homes, including buying and selling them. I also have experience of relatives living in a care home, so I know something of what care homes do. I advise people about dementia issues on an international level, and I'm a Professor Emeritus in dementia studies.

At the end of ten years directing the University of Stirling's Dementia Services Development Centre, I wrote the companion volume to this book, *Dementia: The One-Stop Guide*. It has been very popular, selling almost 40,000 copies, and has been published across the world and in translation. Many suggestions from readers have been taken on board and are incorporated in the new edition, or have already been added to the book section of my website: www.juneandrews.net. One popular aspect of that book was the fact that some information was repeated in

different chapters, to save readers the effort of referring back and forward. You are very busy, so I've done the same thing in this book, in the hope that it will be useful. It means that facts, advice, opinions and information may appear more than once within each theme, and in the book as a whole. The aim is to make it easy for you to dip into the book. I'd hate for you to have to read all of it from end to end to find what you want, though it is written so you can read it like that. Having to flip back and forward in any book can add to my confusion when I'm gathering information. If you're reading this book, your life is probably annoying enough already. Hopefully any repetition is helpful rather than irritating.

Read this book throughout the care-home process – from the moment you begin thinking about the possibility, through the search for the right care home, up to settling in and getting the most out of the new situation. I have a lot of experience and expertise, which I hope will help you during a difficult time.

PART I

CONSIDERING CARE

Chapter 1

The basics

One thing everyone has in common is that we get older every day. Children and teenagers long to get older as fast as possible so they can be independent, go about alone, choose their own clothes and company, decide when to go to bed and when to get up in the morning, drive a car and take risks. Once you've got all that, you take independence for granted. That is, until late in life, when you begin to dread losing it.

Why might someone need care?

No one wants to be dependent and always be told what's going to happen next and have the car keys taken away. It feels as if you are being treated like a child, when you are watched by other people and told that what you want is not allowed, because someone else thinks it is too risky. But the fact is that every day in adult life we get closer to a time when this might happen.

This book is asking you to think about this – whether for yourself or someone else.

You need to understand that just talking about old age, or disability, and even death doesn't make it happen. It is what it is. (Family doctor)

Of course there is stuff you can do to postpone the day when you

become dependent, or maybe prevent it ever dawning. There is a whole industry around prevention, including health clubs, diet plans and experts in the mainstream media, or on social media, telling us what to do. That's backed up by government policies, health-education programmes and even laws, like the law banning smoking in public spaces and the law setting hygiene regulations in the food chain. Becoming ill or dependent is not inevitable. Staying fit and well, and independent until the day you die, is the ideal for all of us. How to do that is not the subject of this book. You can find that out in other places.

You need to have a plan, because even if you take care, a phase could come when help is needed. This book is about how to decide if it's time to get help, how to choose that help and what pitfalls there are along the way.

There's good evidence that we are living better, for longer. Even dementia – the condition that has (according to research) replaced cancer as the disease that scares us most – is not increasing as fast as predicted. The world is a safer place for most of us, and more of us are benefiting every day from improved nutrition, sanitation, disease control, new medicines, road safety, education, safer housing ... the list is endless. No world war for over seventy years. As a result, many more people live into old age than did in the past.

But towards the end of our longer, healthier lives, things may start to need attention. We humans are not machines, but unfortunately, as with an old appliance, component failures occur after long use. This could be impairment of your hearing or eyesight. Or it could be a loss of muscle strength, or mobility problems like arthritis. Technology can't always help. Older people tire more easily. Any one of these issues, or an accumulation of them, can make life much harder. In the end we may need extra help with everyday living from that point until we die. You want to stay as

well as possible for as long as possible, but it might break down.

When you ask me why anyone needs care, it boils down to three things. First, they can't do some important things for themselves, like organise their meals or go to the toilet. Second, they don't live with someone who can take care of that for them, or don't have someone near enough to provide enough care all of the time. Night and day. Third, and this is the remarkable thing, they have some incident that draws them to the attention of the authorities. It could be a fall, or an infection, an accident or just a neighbour expressing concern. At that point, especially if they end up in a hospital, the usual exit door is into care. (Nurse)

People talk about 'deciding' to go to a care home, as if this is a lifestyle choice. For a few lucky people, that's exactly what it is.

Well, when Joyce died, I was very lonely. My family organised some ladies to come in and clean and I tried my hand at cooking, but food doesn't taste the same when you have to eat it on your own. The house was dying without Joyce in it. Here [name of care home] isn't like a nursing home. I brought the car here, so I can still go out for a run. And I have a big room to myself and I don't have to worry about washing my clothes or changing bed sheets or anything. The food's good, and there is always someone to talk to. When the boys come to stay, there's a guest room for overnight and we get the private room to dine, or they take me down the road to the pub. (George, 79, fit)

For many other people, it is not a choice at all.

Mum always said she would never want to go in a care home, but we couldn't keep up the visiting, and the council only puts carers in four times a day maximum, and she needed someone at night because she kept falling trying to get to the toilet. The care coordinator said she'd reached the point where she'd need residential. Now she's there, she

complains all the time and asks us to take her home again. (Oldest daughter of Peggy, 84)

Unlike Peggy, George made a lifestyle decision that he could afford. He could have stayed at home independently, if he'd wanted, and even hired some help. In the event, he didn't want to live alone, and fancied the little touches of luxury in the care home. He knows that if he ever really needs any help, now or in the future, it is there. There were other options that he could have considered, such as sheltered or supported housing, which are discussed in Chapter 2.

How do you decide that living at home independently is no longer what you want or need?

The decision depends hugely on your resources. If you have enough money in the bank, or in the value of your house, you have almost complete control over your decision about when the time is right, and where you want to go.

Some people have children or other relatives who can support them by paying for their care. That's not a legal requirement for children in the UK. It is in other countries, though. Penalties for not looking after your ageing parents in China can include being put on a credit blacklist, being refused a bank account or loans, and losing simple privileges like having a library card.

Last week ... deputy director of the Legal Affairs Office of the Shanghai Municipal People's Government took it upon himself to remind Shanghainese that they can face all these restrictions under the law if they don't visit their old parents regularly. (Patti Waldmeir, Financial Times, 11 April 2016)

‘Filial responsibility laws’ in the US impose a duty on adult children to support their impoverished parents. The UK has the ‘lookback’, where the authorities can check financial records to make sure that the old person did not give away any assets recently to their children, in order to deliberately make themselves eligible for free state aid. (There is more about these financial issues in Chapter 10.)

If you depend on state funding – that is, care provided free by the council – then your position is almost the opposite of George’s. You can’t just decide it is time to give up your independence in exchange for care and company and enter a care home. You must first be assessed by social workers as needing the care. Next, the local authority has to have enough resources to provide the care for your level of need. In some places, people are not eligible for council-funded care until they are extremely dependent.

Councils in rural areas ... have five times less to spend on care of the elderly than those in cities, new analysis reveals. The study by the Salvation Army warns that areas with lower house prices are unable to properly fund social care because they cannot raise enough from council tax and business rates ... evidence of a ‘dementia lottery’ ... typically councils in Dorset would have around £5,762 a head to spend on elderly care – while those in Lambeth in London could have more than £31,000 at their disposal. (Daily Telegraph, 19 July 2019)

In many cases, you might have assigned decision-making about your care to a ‘power of attorney’ (See Chapter 10 for what an attorney can do for you, and why we must all have one. That includes everyone looking at this book for any reason at all, even editors, reviewers and browsers in book shops.) Your attorney can argue your case with the council or any other authority, and make decisions and agreements when you are no longer able to make them for yourself.

In other words, there are many reasons why you may want, or have, to go into a care home, and many factors that will affect your ability to choose. But one thing that shouldn't play a part in your decision-making is scare stories about care homes. Care homes often feature in the news because in a few cases things go wrong. But when you look at the wide scale of health problems they deal with, you want to shout, 'Hurrah for the care homes! Bless them, every one!' In years gone by, those health conditions that are now managed in a care home would have killed you. In other cases you might have spent your last days in misery or isolation at home, or in a big communal ward in a geriatric hospital or psychiatric hospital. Now you can choose to go into a single room in a care home or to have care at home, and the standards of care provided are carefully monitored.

Care-home companies are sometimes condemned in the media, when something bad is brought to light. It would be better to focus on the fact that nearly half a million people live in a care home in the UK, and hundreds of thousands of kind, experienced and dedicated women and men go to work every day and night to care for them. It's a modern-day miracle of love and care. (Of course it's important not to be blind to problems – and in Chapter 7 we look at what to do, if a care home is not that good.)

Here are some common examples of why a care home might be needed:

- deterioration in health
- confusion problems
- breakdown of help
- loneliness, isolation and depression.

Deterioration in health

Dad did well till he had a fall in the garden and got a hip fracture. He'd been looking after Mum – she's got dementia – and I think he got exhausted. Now he looks a bit spindly and has troubles getting around the house, but she needs someone to nip after her when she heads outside in the wrong weather or the wrong clothes. She went in a care home for respite while he was in hospital, but afterwards he couldn't manage to get upstairs to the bathroom any more. They kept him in hospital till they found him a care home, but it couldn't be next to her. Neither seemed to mind, but it was a problem for us visiting. And she's looking great. (Son of a couple in their nineties)

The woman who is now having respite care was being looked after by her husband before his illness. She started to look, and feel, better once she was in the care home for respite. She was well fed and looked after, by a team of dedicated staff, twenty-four hours a day. Perhaps her husband and his family hadn't noticed that he also was getting very tired and depressed and was neglecting himself. So, everyone feels that she's better where she is, and he is able to rest and be looked after himself, especially with his mobility problem. It took an emergency to turn the situation round.

If your older relative has had a fall, or an illness that takes them to hospital, they often deteriorate in their physical health or mobility while there. Some families suspect that maybe the person had already grown weak, and it just showed up after the trauma that took them into hospital. But there is important evidence that hospitals can be bad for your health, when you are old and frail. In hospital it's often hard to sleep, and the patient may worry about what's happening. There is a lot in hospital that puts you off your food, even if it is nicely prepared and served. Older people, especially, are in danger of becoming dehydrated

and confused, and a trip or slip in hospital is common as a result. Delirium – a reversible condition that could cause fast deterioration – sometimes gets missed, and the person goes downhill. The after-effects of delirium can go on for months. All these problems come on top of whatever got the person into hospital in the first place. The risk of infection in hospital is high, so medical staff are keen to get people safely out, as soon as treatment is finished. They also need the bed for someone else. As a result, the person may return from hospital at short notice, weaker and more vulnerable than before.

Situations that were being managed at home, with a bit of support, may have broken down during a hospital stay. That faithful cleaner decides now is the time to retire. The helpful neighbours use the pause to let you know they can't really keep up the twice-daily support visits.

Therefore what might start with hospitalisation for an accident, a fall, a urine infection, chest pain, a stroke, flu or a lung infection can cause a radical reduction in what is realistic. Because of a wide variety of issues – which might include a breakdown of care arrangements, deteriorating health and a well-founded fear from the hospital staff, or the family, that the return home is just not going to work – a hospital stay is often the first step towards a care home. The speed with which this all happens is one good reason for starting to think in advance about what you would do if something happens, and talk about it with the family and others involved as early as possible, before any emergency. Talk about it as soon as you can.

Confusion problems

It is always amazing how many ways a person with dementia can unintentionally cause alarm. Some of the small things can be laughed off. But sometimes it's really not funny.