



Finding a good Dementia Care Home: A guide for you and your loved one



Written by family carers for family carers

About this guide

We are professional trainers with a special interest in dementia. Our team includes members with personal experience of finding a Care Home for someone they love. We've written this guide because we feel that there is virtually no practical, first hand advice available to support anyone starting on such a journey.

The Dementia Training Company is dedicated to raising awareness of dementia, particularly within the caring professions. We train staff at all levels and from all disciplines. Through short, modular workshops, we help staff to understand the unique challenges of caring for people with dementia.

A particular strength of our training is the diversity of our course leaders and contributors. The leaders have direct relevant professional experience. Our fellow presenters are family carers who have devoted part of their lives to looking after a spouse, partner, parent or relative with dementia.



Helping You to Find a Good Care Home

If you're looking for a care home for a relative, friend or loved one, it's probably because you have experienced a crisis.

Maybe you're a sole carer and can't cope on your own any longer. Maybe you have a growing family and there isn't time in the day to give everyone the care and support they need. Perhaps your loved one's condition has deteriorated, meaning that care at home is no longer an option. Or, and this is increasingly common, your relative may be in hospital and no longer capable of living independently.

Whatever the reason, you are now faced with possibly the most difficult and least welcome decision you will ever have to make.

Stress and anxiety

In terms of stress, moving someone you have loved and protected into a care home is on a par with divorce, bereavement and moving house. But it is also very different from these because you, as next-of-kin or responsible adult, are making a life-changing decision on behalf of another – and probably much-loved – human being. This brings with it guilt and anxiety so intense that it can only be truly understood by those who have personally experienced it.

You are where you are because you've been brought here by circumstances that are not of your choosing. You may feel trapped in an endless nightmare or lost in a maze. You feel desperately alone, in despair, and you seem to have precious little support from the "authorities". What you want are solutions and all you can see are problems. Above all you want reassurance. You want to be sure you're doing the right thing. Yet your brain is so scrambled that you find it hard to focus on your immediate needs - or on the long-term needs of your loved one.

You seem also to be living in a whirlwind of meetings, discussions, form filling, visiting and information gathering. It is a time of stress and loneliness. The people you're dealing with may correctly display a professional detachment, but one that appears to take no account of your emotional turmoil. Their priorities seem to revolve around slotting people into available spaces in the shortest possible time. Yours is to find the most suitable place for someone who is very special to you. How are you expected to think straight in such circumstance?

No perfect solution

What is certain is that the solution you find will not be perfect. But you do have the power to make it as good as it can be. And you should take as much time as you need. Do not, however, assume that care you pay for will necessarily be better than that in the public sector. It could be: but cost and compassion are rarely cut from the same cloth. Clearly everyone's needs and aspirations will be different but there are some universal truths. So what follows is not a prescription for success but a few signposts, based on our experience that may help you to your destination.

Guilt and relief

Caring for someone with dementia has been identified as one of the most stressful and demanding things one human being can do for another. You journey together as the disease progresses but sometimes you also travel apart as communication breaks down and you cope with exceptional physical and emotional demands. It is hardly surprising that the imminent change to this chapter of your life should fill you with complex feelings of guilt and relief in equal measure.

Personal support

At a time like this the help and support of friends and relatives is vital. You may have lost close contact because of the demands on your time. But do, if you can, try to build a support network of people you like and whose judgement you trust. Now and in the future, you will draw strength from people who have your best interests at heart.

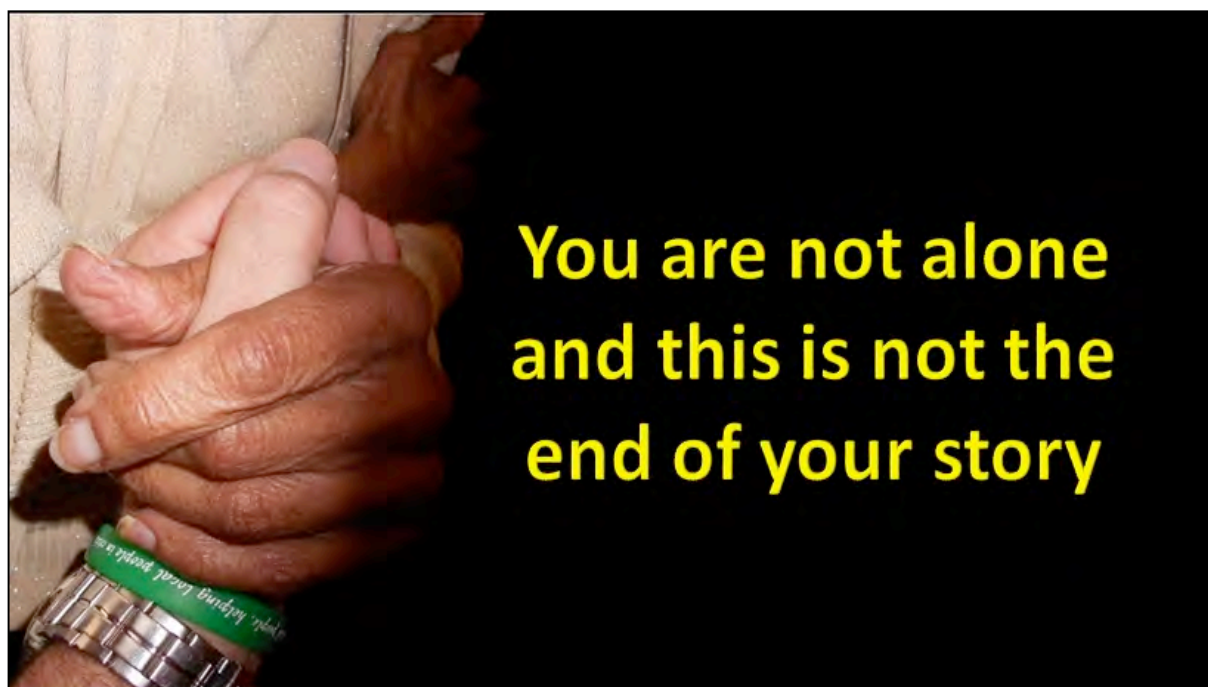
Don't be rushed

The chances are that you have never set foot in a residential care or nursing home. So, you have no previous experience upon which to draw, nor any idea what to look for. And the sad truth is that you may not even have a great deal of choice, as the pressure for places in many areas exceeds supply.

The professionals you're dealing with are also under pressure, and have their own intractable problems to deal with. Quite likely they will have no experience of the strain you've been under or the raw emotion you now feel. Instead of sharing with you they may instead maintain a 'clinical distance'.

That's when you need your support network. It may also help to talk to your GP, Community Nurse, Admiral Nurse, Occupational Therapist or Social Worker.

But when you find a home that you like – and you will – be prepared to dig your heels in. Don't feel you have to take the first available space in order to solve someone else's problem.



Starting the search

Initially you will have a clean slate, no basis for comparison and no knowledge of what's available in your area. So, it doesn't really matter where you start. The first homes that you visit will simply give you a benchmark against which to measure the others.

Many local authorities provide a directory of the homes they manage, or a list of locations. You can also search the Internet as all private sector care providers have details of their homes on their websites, as do many local authorities.

You will probably start by visiting homes that are close by or easy to reach but, wherever you start, do not go alone unless you have no other choice. A second pair of eyes, a level head and the wisdom of a trusted friend are assets beyond value.

Do some research

The only advance information you have will be the blurb you find in a directory or on a website and, as such, it is probably of limited value. More useful is the category of care a home claims to provide. Does it specialise in dementia, for example? Will it take residents who are incontinent? Does it have nursing facilities or is it simply a residential home? The latter is very important as, ideally, you don't want to be looking for another home in a few years' time.

Also think about location, especially if you don't drive. Visiting is time consuming and it can be stressful, particularly in the early days, so you want the journey to be as easy and short as possible. However, it may be worth compromising on convenience if it takes you within reach of a home that you prefer.

At the end of this booklet you'll find some useful links to websites offering support but these are probably most useful once you have some sort of shortlist. You want to avoid being overwhelmed by paper and, sometimes conflicting, advice



It's also worth looking at the CQC ratings of any homes you propose to visit. But bear in mind that these are simply a snapshot of what was observed over a couple of days. For more detailed information have a look at the reports on their website www.cqc.org.uk

You will probably begin by phoning around and arranging to visit some of the homes on your list. Good idea - but be sure always to make one or more follow-up visits, at a time of your choosing and without giving prior notice. If a home objects to this it may be because they have a medical emergency or everyone is busy at a mealtime. Nevertheless, you should be made to feel welcome, and if you don't, you can immediately strike the Home from your list.

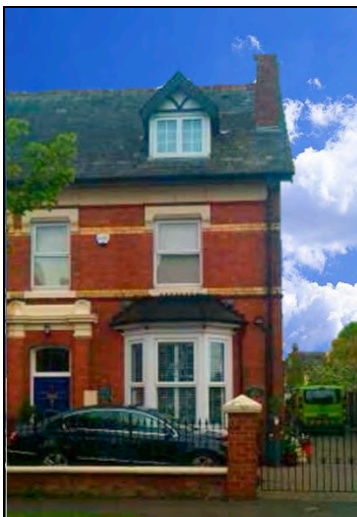


Local Authority or Private Care Home?

First impressions are important but they can also be misleading. Many local authority homes, for example, are not located in expensive neighbourhoods and they often have something of an institutional appearance. This means that your first impression may not be favourable. But go inside and you may be pleasantly surprised.

At the other extreme, you will find that many privately run care homes are in prime locations, maintained externally to a high standard - and with a premium price to match. They are effectively selling a lifestyle and the care may be very good but don't mistake style for substance. For example, how well do they care for high-dependency residents with increasing needs?

For some residents, and this clearly depends on individual family circumstances, an up-market home may feel more like a hotel than a permanent residence, possibly making it more difficult to settle.



Your first visit

When you first visit a care home you may be surprised by the degree of security. There will be some sort of access control: probably a keypad or a bell to operate to gain entry. Similarly, when you leave you will need a code or someone to open the exit door. This can seem a bit intimidating, institutional even, but it's designed for the safety of residents. Remember that many of them will have memory issues and problems with orientation and perception, making it challenging or dangerous to go out alone.



There should be minimal restrictions on you taking your loved one out from the home; bearing in mind the health of your loved one, of course, and any quarantine precautions in place to prevent the spread of infection.

Nor should there be limited visiting times. This is a home, not a hospital or prison! Just be aware of mealtimes and medication needs and make sure that someone in authority knows who you are taking out of the Home. Equally, let them know that you have returned!

Do you feel welcome?

Having gained access, the first person you meet will be the receptionist or administrator. And the greeting you receive will give you a clue as to the culture of the Home. It's not infallible, as we all have off days, but you should form an impression of warmth and kindness.

While you're signing in (for fire and safety reasons) take a look at the reception area itself: décor, information about the Home, pictures of staff, details of the management team and so on. Do you feel welcome or do you feel like an intruder? These first impressions are important.

We hope you've taken our earlier advice and brought a friend or relative with you on this visit. You will probably be met by the home's Manager or a deputy. Hopefully you will be offered some refreshment and taken somewhere private to discuss your needs and those of the loved one for whom you're trying to find a suitable home.

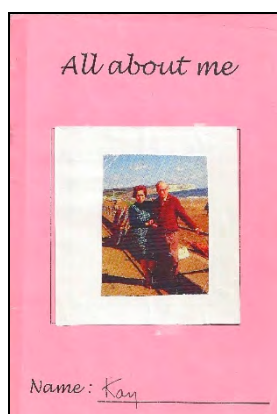
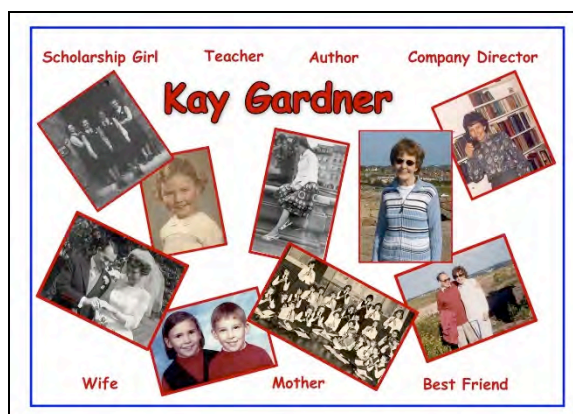
First Impressions

You will be given a tour of the facilities - and this is when your antennae need to be well tuned and when the second pair of eyes is invaluable. Also use your sense of smell. You should not be aware of body odours or other unpleasant smells. Although even in the best-regulated homes there can be unfortunate and unexpected “accidents”!

At the same time, don't be distressed if you hear a resident shouting or using bad language. Some variants of dementia mean that people have mood swings or lose inhibitions. Or they may simply become frustrated by a world that they no longer understand. They may become angry or sad for no immediately understood reason – and this is not a reflection on the Home. What matters is how the carers respond to the situation. They should be sympathetic and intent on restoring calm, by responding sensitively to the person who is distressed.

How are the residents treated? Do the staff introduce you to them? Do they ask a resident's permission before taking you into their room? Are residents treated with respect and dignity? You should not be privy to any care conversations or actions. Staff should not reveal personal information about residents to you unless they have permission.

The modern philosophy is that dementia care should be 'person centred'. This means that every person with dementia is treated as a unique individual with their own wishes, beliefs, routines, likes, dislikes and life history. Listen out for this phrase or description during this visit. Can you see residents being treated in a person-centred way or do they all seem to be doing the same thing at the same time? Are they all being spoken to in the same way? Do the residents appear interested and alert or are they all asleep?



These images are examples of good practice in providing person centred information and support

Dementia-friendly environment

If the Care Home claims to specialise in dementia it must meet certain prerequisites. Residents should be able to move around the home as safely and independently as possible.

A good rule of thumb is this: can you easily find where the lavatories, bedrooms, lounge, garden and exit are? If you can't, neither will residents with dementia. Also, look out for good signage and visual cues.



Lounges, bedrooms and facilities

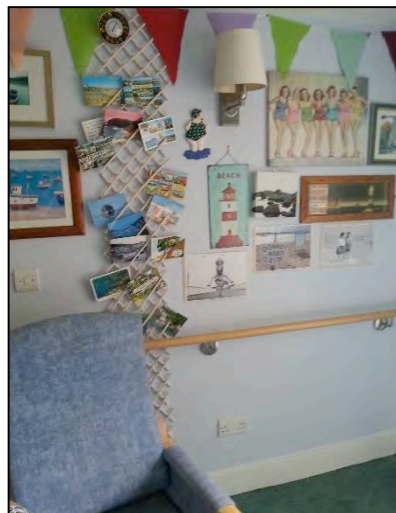
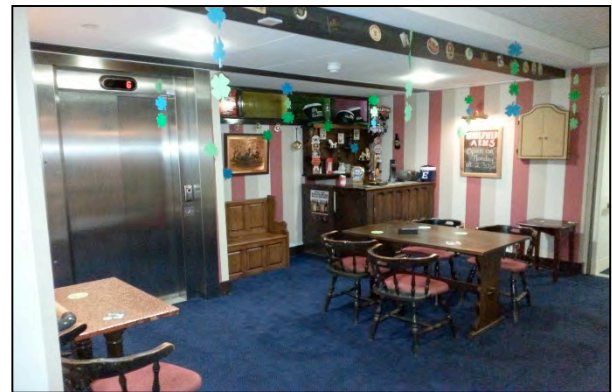
As you go around the Home, observe what's going on and try to sense the atmosphere. Are the staff tense or relaxed? In the lounges, do you hear any laughter or chit chat? Do the carers interact with the residents? Are any activities taking place? Or is there simply a television on that most people seem to be ignoring?

Find out what other facilities are available for residents and visitors. Are there quiet spaces where you can sit and talk? What sort of stimulation is available? For example, is there any sign of picture books, puzzles, tactile objects, soft toys, indoor games, a piano?

Looking at the accommodation, are the lounges and bedrooms clean? Are the bedrooms welcoming and personalised? Do the beds feel comfortable?

Are the bathrooms and toilets clean? Do they look homely rather than clinical? You should not see rubber gloves or aprons or care or cleaning materials of any kind left around the Home.

Check also whether the residents are able to get outside. Do they have access to a garden or sheltered area where they can get some fresh air and sunlight?



These images are examples of good practice in providing a 'dementia-friendly' environment in Care Homes.

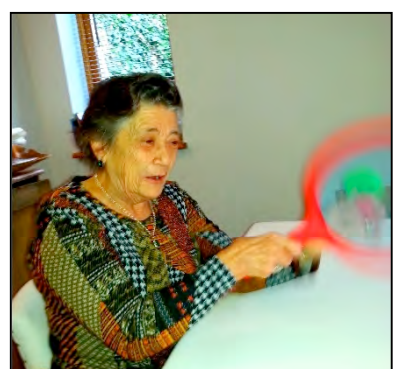
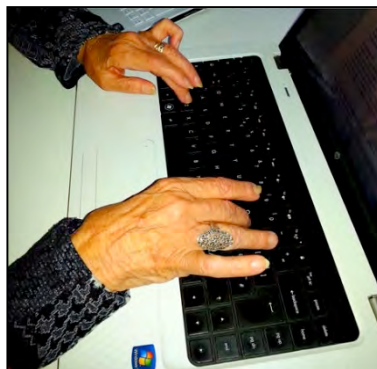
Activities

Following on from your tour of the Home, ask about entertainment and organised activities. How often do outside entertainers visit the Home? Is there a programme of activities every week? How many activity co-ordinators does the Home have? As a rough guide you would expect a 30-bed home to have one full time co-ordinator or two part-time.

If the Home has a nursing wing, find out whether these residents are included in the activities, as their need is as great, if not greater, than those in residential accommodation.

We all know budgets are very tight and activities may well be an area where you find that the care home is economising on staff levels. If so, you might wish to raise this with your local councillor or MP, as activities are essential for the well-being of residents. It is worth questioning home managers about their commitment to this key area. Their response will tell a great deal about the culture of the Home.

If your loved one enjoys a hobby or interest, ask the Manager if he or she would be encouraged to pursue it.



Food and drink

Meal times can be one of the highlights of life for anyone in care. They punctuate the day and bring people together, so it's worth observing what happens, say at lunch. For a start, does the food look like something you would fancy to eat? If residents have difficulty in eating or cutting up food, is there help at hand. Also find out if drinks are served at intervals between mealtimes as older people, especially those with dementia, can easily become dehydrated.

Finally, have a look in the kitchen if you can, talk to the staff and find out about the menus. Look for variety and food that is relatively easy to eat. Is the food cooked and prepared in the Home, and are you aware of cooking smells?



Does the dining room look appealing? Are there other places in the Home for people to eat? If you wish to, are you welcome to dine with your loved one? Also, how are any dietary preferences, allergies and so on catered for?

Personal possessions

You should also enquire about some of the practical aspects of life in a care home. Can your loved one bring in items of furniture, a radio, television, pictures, memorabilia? If this is discouraged it's not a good omen. Also, can they go to their own room during the day for some peace and quiet, or to eat, if they wish?

It comes as a shock to some relatives to find that, clothing in care homes needs to be labelled. Laundry management is a major task and some homes handle it better than others. It's not a deal breaker but it's worth asking other relatives whether clothing gets muddled or goes missing.

You may prefer to continue to do your loved-ones laundry but it will be worth labelling clothes



anyway – sewn on labels are preferable to iron on!

Friends, relatives and the community

Towards the end of your fact-finding mission, try to establish the Home's attitude towards friends and relatives. For instance, is there a room where you can hold a birthday party or other family celebration? Are friends and relatives encouraged to support the activities of the Home? Are they encouraged to volunteer, for example, and perhaps read or talk to residents? Can they get involved in fund raising or linking in to the wider community? Are young people encouraged to visit, to assist with activities and to befriend residents?

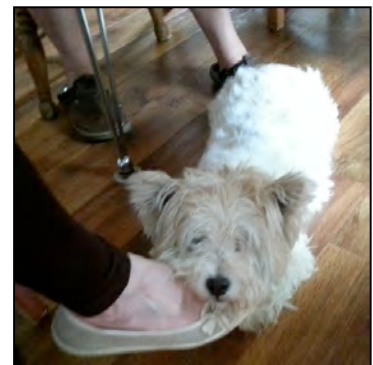
Ideally the Home you choose should be outward looking rather than a self-contained island of care.



Pets

For many of us, our pets are the most precious things. If your loved one has a strong connection to a pet or to animals in general, find out whether this need can be met. Does the Home have a pet? Will it accept your loved one's pet? There are clearly logistic and practical issues here and much will depend on the size of the home and the facilities available.

Are families encouraged to visit with their pets? Some homes welcome pets as they provide stimulation. Some also have 'Pat Dog' schemes and others may have access to farms or organisations which bring animals into the Home.



Religious observance

For some families, the opportunity for a loved one to participate in religious services will be non-negotiable. If this is true in your case then you need to know what denominations are catered for and what the arrangements are. This will largely depend on how good the Home's links are with the local community.

It is equally important that the Home respects the wishes of non-believers and provides alternative activities.

If your loved one has a particular spiritual need that is fundamental to their well-being, tell the Home Manager and ask how they would accommodate this need.

Progressive Care

If the Home you are visiting offers residential and nursing care, find out about the transition arrangements. As your loved one's condition progresses and he or she needs more intensive care, is that available within the Home? Are there arrangements for a seamless transition from the residential to the nursing wing? Or is there a separate assessment process and waiting list for a nursing bed?

Assessments

As you become involved with the care system, you will enter the tangled web of Adult Services and social workers, and the business of Needs Assessments and Financial Assessments. These are beyond the scope of this document but if you are the next-of-kin or have power of attorney, you have the right to be present at any Needs Assessment. These assessments are often the first step in defining the



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Financial Assessments are intrusive and the benefits system itself is opaque. If you need help in this area it's worth talking to one of the charities such as the Citizen's Advice Bureau, Age Concern or Age UK. Also, websites such as the Alzheimer's Society have a number booklets and information sheets you can download. However, this is a complex area and it's probably worthwhile having a face-to-face meeting with someone who understands how the system works.

Having chosen the Home that you feel best meets the needs of your loved one, the Home's Manager will then assess him or her to ensure that the Home can meet those needs. The Home's Manager will also assess whether your relative would fit in with the existing residents of the Home. Be prepared for this, as home environments differ and the needs of people with dementia vary greatly so it's important that new residents can integrate.

You should be present during this assessment. As a family member, friend or relative you should not feel excluded from assessment processes – you should feel part of 'the team' and your input should be sought and valued.

Find the decision maker

In the private sector admissions decisions will probably be made by the Home's manager. With local authorities, there's usually a hierarchy involved and homes often have waiting lists. These lists may be managed autonomously by individual homes, or there may be a list manager responsible for vacancies throughout a given area.

So, our final piece of advice is to identify the decision-maker and make contact. Find out how the system works - and if there is a waiting list, how long it is. If you've found a home that you particularly like, put your loved one's name down on the waiting list for that home and don't accept a place elsewhere. If you do, making a subsequent move may prove very difficult.

If your relative is in Hospital you may feel under pressure to move them into a different home temporarily until a vacancy is available in your chosen home. Try to avoid this and get professional support if possible. Evidence shows that moving someone with dementia can have an extremely detrimental effect and cause the disease to accelerate.

However, you may be overtaken by circumstances and have to take accommodation elsewhere, then fight later for the home you want. (We use the word 'fight' advisedly as you may have to be forceful to get the outcome you want.)

This is a long and unenviable journey that you've embarked upon. Do call on friends and relatives if you can, to help you to make the right choice for your loved one.

But in the end it will be a compromise. Some homes will be better in one aspect: others will be better in another and you have to make your own value judgement.



Useful Contacts

There's a vast range of information available on the following websites, but never underestimate the value of personal experience, and do try to learn from others who have been on this journey.

www.carers.org (help with finding local carers support services)

www.mind.org.uk/ (help with finding advocacy services)

www.nhs.uk/ (help to find your Patient Advice and Liaison Service in your local Hospital)

www.counselling-directory.org.uk (emotional support and counselling)

www.thedementiatrainingcompany.co.uk

www.alzheimers.org.uk

www.ageuk.org.uk

www.citizensadvice.org.uk

www.relres.org.uk (Relatives and Residents Association)

www.cqc.org.uk

www.independentage.org

www.dementiauk.org (Admiral Nurses and Admiral Nurse Direct Helpline)

www.carersuk.org

www.gov.uk/government/organisations/office-of-the-public-guardian



Learning together to improve the lives of people with dementia