



Thinking About Long Term Care?

A booklet for carers
looking at the emotional
and practical issues

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Booklet for carers

This booklet has been written for carers - people who, unpaid, care for a relative, partner or friend who could not live independently without their support. This may be due to illness, frailty, disability, long term condition or addiction.

Introduction

Thinking about long term care for someone we care about can be very bewildering and confusing. It can also be a very lonely task, difficult to share with others.

That's why this booklet was written for you, the carer. It was written by carers, for carers, and is based entirely on the experience of carers. We acknowledge their contribution on page 27.

We hope it will help you to explore questions which affect you and the person you care for when you are thinking about long term care, such as ...

- Are there any options, other than long term care?
- How do I tell the person I care for?
- What will the family think?
- Is it usual to feel so overwhelmed by it all?
- Who can help me sort out what I am feeling?

This booklet won't give easy answers, but may offer better insight into very personal and difficult issues. It will help you to make sense of what is happening to you.

It will explore options, offer ideas and point you in the right direction to find relevant information and someone to talk things through with.

Thinking about Long Term Care

"I don't even want to think about Mum or Dad moving into long term care"

Some people plan for old age and are happy to move to a care home when the time is right. They see it as a positive choice. Others prefer not to even think about it as an option hoping they will never have to make that decision.

As we go through life we plan for all sorts of events: leaving home; getting a job; going to college; finding a partner; having children. We may even take out insurance cover against illness and get as far as planning for our retirement.

But most of us don't dwell on, or plan for, being unable to care for ourself; needing permanent help; the use of a walking frame; being incontinent; needing to be washed and helped to manage the basics of life. It's an aspect of life we would, if we are honest, prefer not to think about.

But in reality this may well happen, as a result of an accident, long term illness or old age. Before it happens to us, it often affects someone else first - a parent or relative perhaps, or a friend, someone we have known for a long time, care about, and often end up caring for.

The need for long term care may come about gradually as the person we care for gets older and less able to manage day to day life. It may happen suddenly if the person has a fall or an illness. Or maybe long term care is needed because we can no longer provide the care we once did. Whichever way, most of us are not really prepared for it.

What do I need to consider?

One of the biggest challenges facing those making decisions about long term care is that there are so many things to take into consideration. How do you decide what's best when there are so many different sides to it?

Well, the first thing you can do is separate the main issues out and explore them one by one. This then gives you a few headings to start with, like:

- Why do I need to consider long term care?
- Are there choices other than long term care?
- How do I talk to the person I care for about this?
- How do I best deal with the emotional issues?
- How can I work through all the changes?
- How do we make good decision?
- Who can help me?

This booklet takes each of these issues in turn and explores how it may affect you. While some issues of moving into a care home are complex and specific to that person, issues like the emotional impact of change will be relevant to most people.

Many people find that even thinking about a loved one moving into long term care is emotional. They may feel overwhelmed with sadness, anger, guilt or may feel relief that their caring role is ending.

You will find helpful pointers to sort out your thoughts and feelings. Take time to work through these, they will assist you to consider the situation from all angles.

A Fairly Typical Family Situation

Before you start exploring your particular situation let's look at a fairly typical family thinking about long term care.

Karen has looked after her father for the past five years since her mother died. He has been living in the old family home, on his own, since then. He was quite independent, but had become a little forgetful. A few times he had left the gas on and had been found wandering the streets. Karen was getting increasingly worried about him.

Karen's partner and their teenage children had helped getting his shopping and doing odd things for him. Karen's family didn't mind all the help she gave her dad as long as she was there for them when they needed her.

Karen's sister worked full time and had limited time to spend with dad. Most of the caring role had fallen to Karen. She did all his cleaning and cooking and took him to all his appointments. She didn't mind as he is her father and he looked after her when she needed him. But demands on her time became increasingly difficult to manage.

Unfortunately, one night during the winter dad slipped and fell. He broke his hip and spent several weeks in hospital. He seemed to deteriorate rapidly and became more confused. It became clear that dad would require a great deal more care if he came home and Karen wondered how she would manage. The hospital discharge team seemed to think that a few hours extra help at home might be enough, and social workers also seemed to expect that Karen would be there to help, just like before.

Karen's sister also thought dad should move in with Karen and her family. She said she would do what she could to help but Karen knew her sister couldn't be relied on. It would be far easier for Karen to give up her work and look after Dad.

Karen's partner said he would support her in whatever decision she made. The children were all upset with what was happening to grandad and stayed out of the way. Karen cried. She didn't know where to turn and what to do for the best. She was full of thoughts and feelings which all seemed to contradict each other.

Had Karen been able to sit down calmly and write down her thoughts, the list might have looked like this:

- I want dad to come home, *but* will I be able to manage if he comes to live with us? How will I manage him and the kids, how will we manage if I have to give up part-time work?
- I want a life of my own, *but* what does dad want? What would mum have thought? Will dad hate me if I don't take him home, and what will other people think if I don't take him home?
- What are care homes like? What will it cost? How would we find a place he might like?
- I don't want to have to wash him
- Do other people feel like this?

A real jumble of thoughts and issues and underlying them all a sense of confusion and sadness that things have to change.

A Digression - The 'But' and 'And' Dilemma

Does any of that sound familiar? Most people find that trying to make a decision about long term care throws up many conflicting and contradictory feelings. They try to explore one side and then a 'but' emerges. I want to do the best for dad **'but'** I also have to work. When you start to deal with situations with 'but' you immediately set up an either-or

situation. You look at the situation as having only one alternative. 'I can do **a or b** but not **a and b**'.

It may only be a small change, however, if you can start to look at decisions as involving an '**and**' instead of a '**but**' things become a little more manageable. For example: 'I want to do the best for Dad '**and**' I want to work', permits you to want both rather than either-or. It also starts you on the journey of trying to find a way through the dilemma whilst giving attention to all parts of it.

Why now?

You may think that the answer to this is obvious, however, its the most important place to begin. You need to think

Am I making this decision because I am exhausted and feel that I can no longer manage; or because the person I care for is no longer able to take care of themselves; or because other people like the doctor or social workers are telling me that I need to consider long term care?

Thinking about your situation [1] ...

Think about your current caring situation and ask yourself, why are you considering long term care now? Are there specific reasons that it has to happen, for example, medical reasons?

Is the person you care for saying it's what they want? Is it linked to your feelings about your role as a carer? Is it to do with how other people, maybe in your family, think things should be?

Explore it as fully as you can, think about the situation and how you feel about it. Write it down.

So why are you considering long term care now?

Once you have tried to answer these questions, did the reasons come easily or were there lots of issues contributing to why now? It is rarely straightforward.

Thinking about your situation [2] ...

Now try to consider all the factors necessary for making a decision about what happens now. Think about what you want, what the person you care for wants and what other people may want.

Make a list that is linked by 'ands'. For example, 'I want what's best for the person I care for and I want a life of my own and I want them to be happy and comfortable and I still want to be involved in their care and I want to be able to go on holidays and I want them to be well looked after'.

List all the things that you would want to happen and link them together.

What sort of list did you come up with ... long ... short ... emotional ... practical. It probably threw up more questions than answers. Hopefully, it will also have highlighted some of the areas where you need more information.

Is long term care now the right choice?

Some people feel they had no choice but to agree to the person they care for going into long term care. They felt the decision was out of their hands. If you feel it is not the right choice for you then you need to explore what services are available to support the care for the person at home. Services such as day care, home care and respite may make the difference between you managing or not. It may be that the person wants to stay at home and may be able to do so with extra support.

Thinking about your situation [2] ...

Think about what it would take for the person you care for to remain at home. Think about all the practical day to day tasks that they may need help with.

If you provide most of the care think about what extra help and support you may need. Write it all down, don't leave anything out, you need to be realistic and look at all the things that need to be done.

This exercise may highlight that it might be possible for the person you care for to stay at home a little longer, providing they (and you as the main carer!) get additional help. Or it may highlight that the extra help and services needed would make it an unlikely option.

Scenario 1: Extra help at home

If you want to pursue the option of the person to remain at home then seek help! Speak to the social workers or health professionals involved. Contact your GP and your local Carers Centre - they will help you find out about additional services for the person at home. Your local Carers Centre can direct you to all the available services and may be able to support you in making your case.

If staying at home is what you and the person you care for want then don't give up. Explore every avenue. If in the end the person you care for still has to go into long term care you will know that you have tried everything and this was the best option left.

Scenario 2: Caring at home is no longer an option

The last exercise may have highlighted that caring for the person at home is no longer an option. It may seem as if you are stepping into new territory now. Big changes on the horizon, a new language, different people to deal with and a whole new range of feelings. At this point the main concerns many carers have are practical. Questions such as:

- What are the different types of care home?
- How will we find a good home?
- How much will it cost?
- How will the care be funded?
- What's my position or role in relation to the person I care for?
- Where can I find information or someone to help me?

To help you answer these questions, the final pages of this booklet (pages 21 - 26) deal with some of these practical issues. There is also information on useful leaflets, booklets and websites, as well as contact details, on page 26.

However, information doesn't always make sense on its own. Sometimes its more helpful to sit down with someone to talk through all the practical implications. If this is the case for you then, again, contact your local Carers Centre. Contact numbers are listed in the back of this booklet. They won't be able to make the decision for you, neither will they tell you what to do. But they will understand what you are going through, give you time and space to talk through all the issues, and help you with information about all of the options.

How do I talk to the person I care for about moving into long term care?

At the same time as you are trying to work through all the practical considerations, you may also be wondering how you can best discuss the situation with the person you care for.

It may be that the person has been fully involved in all discussions and is able to express their opinions and help planning ahead. However, it often happens that the person is quite unaware of the problems, or is in hospital following an illness or accident and does not want to consider anything other than going home.

Another situation carers are often faced with is when the person they care for is at home and becomes increasingly unable to care for themselves. Or the person may no longer recognise the carer as a relative or friend. They may not be in the position to express their views. Whatever the situation, discussing a move to a care home may prove very difficult.

Let's explore that situation. You may feel upset thinking this through, so give yourself enough time and space to really explore your thoughts and feelings.

If it feels appropriate, do it with other people involved in the decision. Or discuss what emerges for you afterwards with someone you trust.

Thinking about your situation [4] ...

Imagine you are in the position to discuss a move to a care home with the person you care for.

- *Think about the best time and place for this discussion*
- *How are you feeling, what thoughts are in your head?*

- *How do you think the person you care for is feeling?*
- *How do you imagine the discussion going?*
- *Is it difficult? Sad?*
- *Are you get upset? Angry?*
- *Is the other person?*
- *What do you imagine will happen?*

Now put yourself in the situation of the other person. Consider their thoughts and what's important to them. How would you react if someone was having to talk to you about moving into long term care. Think about how you would think and feel.

- *How would you like to be told?*
- *How would you like to be involved in the decision making?*
- *Who would you like to tell you?*
- *What would make it less difficult for you?*

And finally, consider what is happening in your situation and see if there is something that would make it less difficult?

- *Think about things that are achievable.*
- *Would it help to have someone else with you?*
- *Would it help if someone else discussed it with the person you care for?*
- *Think about what would make it different to how you imagined in the previous exercise.*

When you start talking to the person you care for about moving into a care home you can feel embarrassed or upset

about the strength of your feelings. You may swallow them, deny them, get angry at other people or drown them in food, alcohol or anything else that puts these feelings out of our awareness for a short time.

The one thing we can say from all our work with carers is that feelings hurt. In this situation you may want to cry, shout, scream, feel relieved and unburdened or rant at the world in general. So might the person you care for. Its alright to do so.

Whatever you and the person you care for are experiencing it's part of your lives together and may need to be acknowledged. People often want to protect those they care about from feeling sad or upset, however, if that is what they are genuinely feeling then it denies them the right to their own feelings. People wouldn't stop someone experiencing feelings about a happy event or change so why do they do it if it's a difficult or upsetting event?

How do I start the conversation?

Taking what you have written in the previous exercise think now about how you begin the discussion. Sometimes you have the opportunity to pick the time and place, sometimes you don't. Thinking about what you want to say and how you feel can help you start the conversation.

It can often be helpful to begin with expressing to the person that you are finding it difficult. Share with them what's happening for you.

Give the other person the opportunity to say how they feel. They may not want to move into long term care, on the other

hand, they may. They may feel upset, angry, they may be withdrawn and quiet. Whatever they feel it is right to respect their feelings and allow them to express them.

But what happens if there is no means of communication open to you. What if the person you care for no longer recognises you, can no longer express their feelings or opinions? It is still helpful to tell them what is happening and how you are feeling. Try to tell them that you can understand how they may be feeling. They may not be able to respond to you. However, that doesn't mean they don't hear what you are saying.

Dealing with Feelings

The range of feelings you can experience in this sort of situation is huge. You can feel sad, angry, upset, guilty, relieved, distraught, calm. Sometimes you can feel some of these emotions, or you may feel all of them and more. This is perfectly normal.

When faced with any change you not only need to adapt practically to the changes, you also need to adapt your emotional life to those changes. No matter why the person you care for is moving into long term care; whether they have chosen this move for themselves; or if it is something that has to happen due to changes in their or our circumstances, the emotional response you have to those changes will be similar.

Some changes are sudden, as in a crisis, others move up on us gradually. Whatever way they come they will all involve a process. How you respond to change is similar in whatever circumstances the change occurs. There is a process and you can expect to feel different things at different times within that process.

What happens when things change?

What tends to happen first - no matter whether the change is for the good or not - is that you may not believe it is happening. You may feel numb as if in shock. This stage may last anything from a few hours to weeks depending on what type of change we are dealing with.

Then you may deny that change will cause you any difficulty. You may even deny that change needs to happen at all. You may say that no matter what, it doesn't matter and you will continue as before. Think of all the lottery winners who say that the win won't change their lives - of course it will - but initially it's too difficult to imagine how their lives will change let alone start to make those adjustments. So, you hold on to what is safe and familiar.

Once you accept that change is happening to you, you tend to start feeling down or depressed. You may begin to wonder if you can manage. You know that life is changing but, as yet, do not know fully how life will be different or how you will manage. It is very common at this stage to also feel angry. You question yourself - could I have done something to make it different? You may get angry - why me, why him, why did it happen to her, its not fair. You may feel guilty about having these thoughts and feelings. Its natural to feel these things. After all you life has changed as well. Its maybe not what you wanted for yourself or the person you care for.

Dealing with Guilt

You may start off by feeling relieved. The price of caring can be heavy for some people. You may feel that at last you have got your life back. No more worry, being able to relax for the first time in months or even years. Sometimes though, just when

you start to feel a lessening of the load you also start to feel guilty. You wonder if you should feel relieved; if you are bad for feeling that way. The clear answer here is no. Its normal to experience the feeling of guilt, however this does not mean you have done anything wrong. It means that you are not used to feeling other things. Things like not being tired, being happy, wanting to do other things with your life. Allow yourself time to get used to these feelings and to enjoy them.

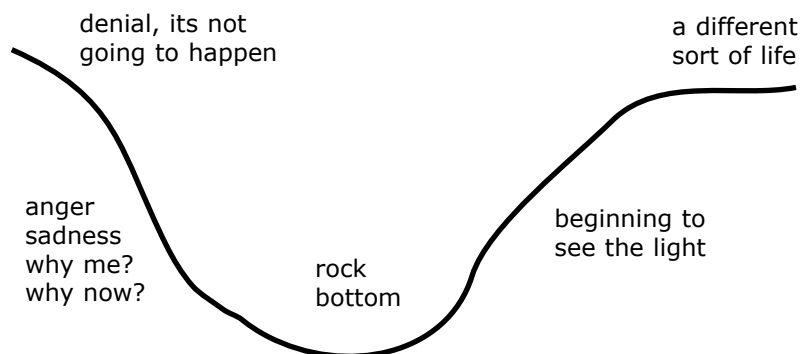
Sometimes though the person you care for, who is also experiencing similar feelings about change will try to instill in you a feeling of guilt, about making them change. Again this is normal and needs to be seem as part of the process of change. As we have said before even if we choose the changes in our lives it doesn't mean that we will always like them.

The person you care for may be frightened or worried about the move. Worried about how they will be treated in their new home, concerned about being left, wondering how often you will visit. It's no wonder they can lash out or be tearful with those they care about. Try to help them express how they feel, if they can, about the move.

This is a time of mixed feelings - sadness, anger, upset, fears about the future, relief. This may continue for some time. Some carers feel worried that they are experiencing these sorts of feelings. They are usual and normal and if you accept them they can help you in the next phase.

You will know when you are in the next phase - it's when you hit rock bottom. When you realise that this is it now. Things are not going to go back to how they were. This is how it is now and you begin to find a degree of acceptance in the situation. Some people find it a very sad time but often tinged with a lessening of tension. They begin to accept the reality of the situation.

The process of change



The 'rock bottom' phase may last anything from a few days to weeks or even months. Eventually though you begin to move on and start looking forward to a better future. You may start to do new things, start to plan more. Maybe you recognise that you feel better about where the person you care for is now. Maybe you are getting to know 'the system' a bit better. Maybe the person you care for is a bit happier.

This is the stage at which you recognise that the change has happened and that you have adapted as best as you can to it. Life moves on whether you want it or not!

What can I do if change is not straightforward?

Of course life is rarely this simple or easy, especially when trying to adapt to such big changes in our lives. You can get bogged down in practicalities. It may not be until months after the event that you begin to feel the emotional impact. You can sometimes find yourself stuck in the middle of family disagreements.

Remember Karen and Brenda at the start of this booklet. Karen wanted what was best for her Dad and wanted a bit of life for herself. Her sister wanted Karen to give up her life to look after Dad, whilst not being prepared to do anything to help. Conflict between the sisters was obvious.

Often one person in a family can be identified as 'the caring one' or the 'practical one' and ends up making all the decisions, or taking on the caring role or doing all the finding out and then others come in and say they should do it differently.

If this sounds familiar then you may benefit from talking things through with someone outside of the family. A support worker at your local carers centre, or a counsellor. Some Carers Centres have counsellors available to help you work through difficult situations. If not, your GP may be able to refer you to someone.

Remember there is help at hand. No one can make the decision for you, however. Support is available to help you make sense of what is happening, help you to access relevant information and explain the practicalities to you.

Dealing with the practical issues

Much of the stress of moving home is associated with worries about making the right decision and taking steps into the unknown. Such concerns can't be completely removed. But access to practical and detailed information can do much to reduce our worries. Good information allows thorough planning and preparation, and being well prepared will ensure that people make informed decisions and better choices

How do I find a place in a care home for the person I care for?

You may be a carer of someone who currently lives in their own home, or who lives with you, or who is in hospital. In any case the first step to moving to a care home is a **community care assessment**. This assessment is carried out by the local authority's Social Care department.

Getting an assessment

You can contact Social Care services and request an assessment for the person you care for. The contact details for Edinburgh and the Lothians are listed on page 26. If the person that you care for is in hospital then an assessment may be carried out as part of the hospital discharge process.

What happens during the assessment?

An assessment can be carried out by a social worker, occupational therapist or community care assistant. There will be questions about the person you care for's lifestyle and how they manage daily living tasks. It helps to note down beforehand the tasks which you do regularly for them.

Once complete, the assessment will be written down as a record which needs to be signed by the person you care for,

and they will be given a copy. If an assessment recommends a move to a care home then you can begin to look for one suitable to the person's needs.

A carer's assessment

New requirements put in place by the Community Care and Health (Scotland) Act 2002 ensure that carers are treated as partners in the provision of care. This means that the support you currently provide and your views should be taken into account.

You have a statutory right to request a carer's assessment which aims to determine your needs as a carer. The assessment is an opportunity to look at all aspects of your life such as family, employment, social and leisure activities, health and support.

To request a carer's assessment, contact Social Care services in your local authority area (see page 26 for details).

Searching for a care home

Following the assessment, and if a move to a care home is recommended, a social worker will be allocated to support you. They will be able to advise on the type of care home the person you care for requires and may provide you with a list of care homes that Social Care are prepared to support.

The Care Commission can also provide a list of registered care homes, and their inspection reports. See page 26 for contact details. If you have access to the internet you can also search for care homes at: www.carebooking.co.uk/search/secure/common/welcome.aspx

What to look for in a care home

Once you have found out about care homes in your area, get in touch and ask them to send a brochure. You can arrange a visit or ask for someone from the home to visit you. Write down the things you and the person you care for want to ask and bring the list with you on visits.

A care home should be homely, safe and secure to enable people to carry on leading as full a life as possible. Don't be embarrassed to ask lots of questions, and have a good look around. Here is a list of some things you may wish to think about:

- **Location:** Is it close to local amenities and your home?
- **Ambience:** What is your first impression? Homely or institutional? Does it smell clean and fresh? Do residents appear happy and active?
- **Staff:** Are there enough staff to meet the care needs of the residents? How do they behave? Do they talk to residents, encourage them to do what they can, or take over?
- **Accommodation:** Do residents get their own room? Is it big enough? Can they bring furniture and other personal items with them? Are they allowed to entertain visitors in their room? Is food allowed in room?
- **Facilities:** Are there visiting hairdressers, chiropodists, physiotherapists, opticians, dentists? Are these services included in the cost of the home?
- **Freedom:** Are safeguards in place to protect vulnerable adults from leaving the home unaccompanied? Are residents allowed to close their doors? Are they allowed alcohol and can it be kept in their room? Can they decide when to get up and when to go to bed?
- **Meals:** Is a choice of good quality, nutritious meals? Can people decide when to eat? Are there facilities to make snacks?

- **Pets:** Are pets allowed in the care home?
- **Activities:** What activities are provided by the care home? Are trips arranged outside the care home? How regular are the activities? Are particular interests catered for?
- **Keeping in contact:** Do residents have access to telephone, fax, email and internet and are there any restrictions on use? Are there set visiting times? Can visitors stay overnight? Are children allowed?
- **Having a say:** Does the care home involve residents and carers in the planning and provision of services? Is there a residents' committee? How does the home handle problems?

The Care Commission and National Care Standards

All care homes are registered and inspected by the Care Commission (see page 26 for contact details). It has a duty to inspect homes twice a year to ensure they follow the National Care Standards. These standards were developed to regulate the quality of care across all care services. They set the minimum level of provision so that you can be assured that a registered care home will be performing to that standard.

Comments and Complaints

If you are unhappy about any aspect of care provided by the care home, you can raise your concerns or make a formal complaint. In the first instance you should speak to a senior member of staff or your social worker. You can also make complaints directly to the Care Commission (see page 26).

Paying for care

If someone is assessed as needing to live in a care home, then their finances have to be assessed. This assessment takes into account the capital and income of the person moving into the

care home. Capital includes property, investments and savings in that person's name. Half of any capital in joint names will be taken into account.

The value of property is not treated as capital if the person's spouse or partner, relative over 60 or a relative under 60 with incapacity continues to live there. If a carer (who is not a spouse or partner) has been living in the house this *may* mean the value is disregarded.

There are upper and lower limits which define how much someone needs to pay. These figures change in line with inflation and are included in the revised versions of Charging for Residential Accommodation Guidance (see page 26 for details). From April 2009, if someone going into a care home has more than £14,500 in capital or income, and less than £23,500, then they contribute £1 per week for every £250 above £14,500. If they have over £23,500, they will be asked to pay the full cost of care.

Some types of income are disregarded or partially disregarded however pensions and state benefits are assumed capital from income. Care home residents can get 50% of their private pension paid to a spouse who continues to live at home.

If assessed as needing personal and/or nursing care, people over 65 entering care homes are entitled to £159 for personal care and £231 for personal and nursing care. People under 65 assessed as needing nursing care are entitled to £72. These sums are deducted from the care home fees.

Charging procedures can be complicated so it is worth seeking advice. Carers living in Edinburgh and the Lothians can contact VOCAL's Carer Support Team on 0131 622 6666. See page 26 for a list of useful resources on paying for long term care.

Contacts and resources

General contacts

Age Concern Scotland	0845 833 0200
Care Commission	01382 207100
Social Care Direct (Edinburgh)	0131 200 2324
Social Care (West Lothian)	01506 777777
Social Care (East Lothian)	0845 603 1576
Social Care (Midlothian)	0131 271 3900
Scottish Government publications (Blackwells)	0131 622 8222

Carer support

VOCAL	0131 622 6666
VOCAL Counselling	0131 466 8082
VOCAL Midlothian	0131 663 6869
Carers of West Lothian	01506 771750
Carers of East Lothian	0131 665 0135
Edinburgh Carers Council	0131 554 5153
MECOPP	0131 467 2994

Useful booklets and websites

Charging for Residential Accommodation Guidance	Scottish Government
Money Matters (2 booklets looking at general information and legal issues)	Social Care Direct (Edin)
Free Personal and Nursing Care in care homes	Social Care Direct (Edin)
Moving on (explains what happens when you move from hospital to care home)	Social Care Direct (Edin)
Local authority charging procedures for care homes	Age Concern Scotland
www.carecommission.com	Inspection reports
www.carebooking.co.uk/search/secure/common/welcome.aspx	Care home searches

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