STATES OF JERSEY

Health, Social Security and Housing Panel
Long Term Care

FRIDAY, 27th JUNE 2008

Panel:
Deputy R.G. Le Hérissier of St. Saviour (Chairman)
Deputy A. Breckon of St. Saviour
Deputy S. Power of St. Brelade
Professor J. Forder (Adviser)

Witnesses:
Ms. C. Keenan (Manager, Ronceray Care Home)
Ms. M. Byrne (Deputy Manager, Ronceray Care Home)

Deputy R.G. Le Hérissier of St. Saviour (Chairman):

We are very pleased to welcome you and we will waive the introductions. We are going to start slightly formal, partly because we are, and partly of course the machine is switched on. There is a transcript done so we make sure that everybody's name is recorded. You have also received or you should have received through the mail just the word about your status as the witness, that the evidence that you give is sort of protected evidence. So we are very pleased to see you here. We will introduce ourselves and then we will ask you.

Deputy A. Breckon of St. Saviour:

Alan Breckon.

Deputy R.G. Le Hérissier of St. Saviour:

Malcolm who is the scrutiny officer. Roy Le Hérissier, I chair this sub-panel.

Deputy S. Power of St. Brelade:

I am Sean Power.

Mr. C. Ahier:

Charlie Ahier, Scrutiny Officer.

Professor J. Forder:
Julien Forder.

Deputy R.G. Le Hérissier:
Julien is the adviser to the panel. So if you would like to say who you are and your role?

Ms. C. Keenan:
I am Carol Keenan, I am the Manager of Ronceray Care Home.

Ms. M. Byrne:
I am Mary Byrne, and I am the Deputy Manager of Ronceray.

Deputy R.G. Le Hérissier:
Okay. Well, it is very nice to see you and thank you for coming. Can you tell us, before we launch into a little discussion on dementia and dementia care, can you tell us, Carol, what kind of home you run and what services you offer?

Ms. C. Keenan:
We run a ... it is a 21-bedded care home, a sort of home-from-home quite cottagey looking, it is not big and intimidating and over the years ... it was commenced in 1993 by a local couple but over the years it has become more dementia care, to the point where I have undertaken a degree in order to register it at the end of this year as an E.M.I. (Elderly Mentally Infirm) unit because I would say that 95 per cent of our residents have some degree of cognitive impairment, and therefore we need to ensure that we provide dementia care to a high standard, so we have taken up the staff training and everything to gear ourselves up to re-register under a different umbrella, as it were.

Deputy R.G. Le Hérissier:
We do not obviously need the details but in terms of ownership, are you owned on the Island or are you part of a bigger ...?

Ms. C. Keenan:

No. We were locally owned by a local couple until March 2006 and then it was ... the couple that owned it retired to Spain and it was purchased by an English gentleman who also owns 5 or 6 care homes in the U.K. (United Kingdom) as well as hotels. But our unit is run on a separate basis to the others, it is not ... you know, it is not in that group, as it were, we are run separately.

Deputy R.G. Le Hérissier:

Okay. So obviously from your experience of dementia how big a problem do you think it is growing to be on the Island?

Ms. C. Keenan:

A big problem. You do not see, or we feel over the years because both Mary and I have both worked in the same place since 1993, and at that stage we started with 11 beds and increased in 1997 to 21 and you could tell that our admissions at that stage were basic residential care. People that perhaps felt they wanted to come in to have company or, you know, their daughter or whoever they were living with at the time or by themselves could not provide a daily routine as such because they were out to work and things, and they used to come in quite able-bodied and things like that, whereas now with the good community service that is available people are coming in at a later age but with signs of dementia and obviously the ageing population and I also feel that people are more educated on dementia and more ... they feel better to go to the doctors, so they get an earlier diagnosis as well, so we see most of the people inquiring for beds and availability have got some degree of dementia.

Ms. M. Byrne:

We have not at the moment got enough beds to fill the demand.

Deputy S. Power:

Really? So you are full all the time?

Ms. M. Byrne:

Yes, mostly.

Ms. C. Keenan:

Mostly. We have one empty bed at the moment and we have had 3 people to look at it and we have kept it for this person that came first.

Ms. M. Byrne:

To such an extent that we are hoping ...

Deputy S. Power:

Almost a case of first-come, first-served, is it?

Ms. C. Keenan:

Really, yes.

Deputy A. Breckon:

Where do you get the referrals from? Is it just word of mouth?

Ms. C. Keenan:

A lot of it is word of mouth. A lot of our residents, we have had residents in the past that luckily thought we ... you know, we provided a high standard and they have said to friends and things, but we do get an awful lot from social services as well. We tend ... I think as well because we do not tend to be on the expensive side of the market, we are sort of middle of the road, and the affordability bracket for some people in the private sector.

Deputy A. Breckon:

What level of staffing have you got?

Ms. C. Keenan:

One to 4.

Deputy A. Breckon:

One to 4. Is that a requirement from ...?

Ms. C. Keenan:

The dementia care is one to 7 and normal residential is one to 10, but we just feel that because we are small that we can provide that level of staffing patient ratio.

Deputy R.G. Le Hérissier:

How easy is it to recruit staff on the Island?

Ms. C. Keenan:

Quite difficult, really. One, because the level of pay in the private sector is not as good as in the public sector, and also the training, you train somebody up, both Mary and myself are N.V.Q. (National Vocational Qualifications) assessors and things and you train them and then they tend to get poached by other organisations that can afford to pay higher wages.

Deputy A. Breckon:

Can I ask you about fees? You mentioned you are middle of the road, but what is the scale of the fee structure from one end to the other, in your knowledge?

Ms. C. Keenan:

Our most expensive is ….

Ms. M. Byrne:

Not ours, Carol. You mean the whole business as a whole? He means different homes.

Ms. C. Keenan:

From £680 to £1,400.

Deputy A. Breckon:

Would G.P.s (General Practitioner) contact you?

Ms. C. Keenan:

Yes.

Deputy A. Breckon:

You have a sort of range of contacts?

Ms. C. Keenan:

We do have G.P. referrals, yes.

Deputy A. Breckon:

Health? Do you take any patients from ...?

Ms. C. Keenan:

From the Elderly Mental Health team, that is based at the Poplars. They make referrals to social workers and things, often people are taken into Beechwood for a 6 week assessment, which is at St. Saviours and then if they are assessed as needing permanent placement they will phone up to see if we have got a vacant room.

Deputy A. Breckon:

You do not keep beds specifically for them?

Ms. C. Keenan:

No, because we have only got 21 beds we have never had enough vacancies in order to contract beds out to Health and Social ... you know, we have not been able to do that. We are hoping to extend ... plans have gone through to Planning to put us up to 25 with an extra 4 rooms so ...

Deputy S. Power:

Can I just ask a couple of questions in relation to patient ... not patients, client profiles. In your experience, the 2 of you have been there quite a long time, the profiles of dementia, just roughly what has been the youngest that has come in, the oldest that has come in, what is the split between male and female and just kind of run us through.

Ms. C. Keenan:

Females are higher mainly because females tend to live longer, so you do get a higher proportion of females being admitted. As to the youngest, I have requested from

Christine Blackwood, the Regulations Officer recently, a dispensation for a younger lady. So although we are Elderly Mental Health we have got a younger lady with dementia and our eldest, I have got one of 97 and one of 96.

Ms. M. Byrne:
We did have one of 104.

Ms. C. Keenan:
So, you know, it is a very wide ... and I think there is more ... there is going to be more now it has become more ... people are more educated and we will find that there are more people of a younger age with dementia.

Deputy S. Power:
When you say "young" do you mean in their 50s and 60s?

Ms. C. Keenan:
Yes, a frontal lobe dementia really develops sort of late 40s to 60s and that is really traumatic.

Deputy R.G. Le Hérissier:
Given the pressure on services and you said that people are coming quicker to their G.P.s and so forth but are you getting people ... because there are more people with dementia and we are better at recognising it, does that mean you are getting people with lesser symptoms or are you getting people with more serious symptoms coming in, so to speak? More serious management issues?

Ms. C. Keenan:
It varies, really, as to when ... you know, like you might get a husband that can cope with his wife at home while she has got minor symptoms and then they will come in with severe symptoms, or people that perhaps live with a daughter and son and they cannot cope with them, even with the minor symptoms, so it is all varying levels that they come in.

Deputy R.G. Le Hérissier:

Do you find, Carol and Mary, that the services you have to provide in your home, are you having to offer more varied services and more complex services or support?

Ms. C. Keenan:

We ... I do not know, I think it is because we are quite small and we are very fortunate that we can provide a family centred service, so that we have got an open door policy to all family. The families ... we try ... we have got a big thing that I do not like the stigma associated with dementia and I speak on that from personal experience when my mother suffered dementia and my father would not go into a pub for lunch, et cetera, because she might kick off, as it were, and he was embarrassed, you know, and other people were embarrassed although I used to go with them, and we have come across that as well in the workplace, so we provide like ... I will provide a carer to go out with a husband whose wife is a resident with us, so that he has got support and things like that. So the services are ... it is not only the resident that you have got to think of, it is about the extended family, as with this younger lady, that is traumatic to them. So it is a bigger picture than just looking after that resident, you have to sort of treat them as a holistic package, for the whole thing.

Deputy A. Breckon:

Do you get any support from the health authorities?

Ms. C. Keenan:

Excellent support.

Deputy A. Breckon:

What about to supplement people who might have special needs? Would they, say, provide some financing for something like that or is it left to the family?

Ms. M. Byrne:

It is mostly left to the family.

Ms. C. Keenan:

Mostly left to the family.

Ms. M. Byrne:

They provide a certain package and that is it.

Ms. C. Keenan:

The Poplars are excellent, though. Dr. Menendez, Dr. Wilson and the Community Health Team. We have a wonderful relationship with them and they are there at the ... just a phone call away, they are there to support us. We could not ask for better service.

Deputy R.G. Le Hérissier:

Everyone is full residence, you do not have people who in a sense pop in and out?

Ms. C. Keenan:

No. That is something I have put in my notes for the future which I think could be ... assist people to live longer in the community in that if perhaps we could be given on top of our in-house residence as it were, have like a day centre where we could be allowed to take an extra 3 from say 9.00 a.m. until 6.00 p.m. We could give them a daily routine, we could employ the extra staff in order to cover that amount but then they could go home to their husband, their daughter, their son, whoever at the end of the day and that would allow them to stay and I think that would be good. You know, they could just come in for their meals and their activities, even if it was Monday to Friday.

Ms. M. Byrne:

I mean, the Poplars do provide that but if more people are going to have dementia then that is going to be a bigger problem and they would either have to increase the number that they could take or it would have to be that they would allow homes to do that sort of care as well, because at the moment we cannot.

Ms. C. Keenan:

If you are like us, we are very fortunate in being in the centre of St. Martins and we have got a good relationship with like the school, the church, the W.I. (Women's Institute) and people know us so if people can come in on a daily basis when they need full-time care it would not be such a big wrench.

Deputy S. Power:

Can I ask a question on respite beds for dementia? How is that handled?

Ms. M. Byrne:

We do not have as such, we have not got the room. We will take, if we have got a room empty, then we will take respite. We are quite happy to, but we have not got a dedicated respite room.

Deputy S. Power:

So within the general health provision on the Island is there a provision for respite ... for the carer getting a break with someone with dementia?

Ms. M. Byrne:

Not really.

Ms. C. Keenan:

Not really. Beechwood are very good within the States system. They will take respite people.

Deputy S. Power:

What is the bed capacity there? Is that if those beds ... availability, as distinct from a respite?

Ms. C. Keenan:

Yes, but I could not guarantee for sure but I think you can book in advance a bed. You know, if you want to go on holiday or something.

Ms. M. Byrne:

I think the old Overdale unit I think used to provide but of course that is no longer there.

Deputy S. Power:

They did. That is why I asked you.

Ms. C. Keenan:

I know Beechwood do, but then it is a bit more hospitalised obviously with, you know, routine and things, but they do provide respite care.

Deputy S. Power:

So at the moment there is no provision for respite beds anywhere on the Island?

Ms. C. Keenan:

Not that I know of. Not for dementia.

Deputy S. Power:

For dementia sufferers and for carers?

Ms. C. Keenan:

Not that I am aware of. Unless the other dementia units do, in the private sector but I am not aware of that.

Deputy S. Power:

How many other dementia units are there apart from ...?

Ms. C. Keenan:

There is one at La Haule Residential Home and Villa Beaumont that has just opened. Those are the only 2 E.M.I. units.

Ms. M. Byrne:

There was another one that has just closed.

Ms. C. Keenan:

Yes, and Ingleby has just shut so ...

Deputy R.G. Le Hérissier:

How many capacity did Ingleby have?

Ms. C. Keenan:

16, I think.

Deputy R.G. Le Hérissier:

16?

Ms. C. Keenan:

Yes, but that is shut now.

Professor J. Forder:

But there are a few places in residential care homes that do take people with dementia, is that right?

Ms. C. Keenan:

Most residential homes take people with dementia but to have sort of care direct for the dementia sufferer ... you know, you can put dementia people in care homes but you still need the staff to be trained because it is a specialised field. Very different skill.

Deputy A. Breckon:

You work with it all the time. Something we were discussing earlier was we have done a thing with the schools quite recently. How do you think we can understand it better? With the benefit of your experience how can youngsters and the rest of us coming through, how can we ...?

Ms. C. Keenan:

More education, really. The Alzheimer's Society is brilliant and perhaps they could be approached to sort of bring it to the forefront. I think we need education across the board, not just for homes that look after dementia sufferers, because we have had experience where a resident has gone into hospital and they are just sort of forgotten, in a way, and that is not through any fault of the staff. The staff are there to treat the fractured leg or the chest infection and have got no education in dementia whatsoever, and it is a specialised subject and you know, we can supply staff and we will send staff down to sit with them and feed them and talk to them, but these residents have

become so frightened of changes of surrounding and really something like perhaps a dementia liaison nurse that is based in the hospital that can go to different wards and A. and E. (Accident and Emergency) or something for admissions that come there would be an idea as well.

Deputy S. Power:

Sometimes you will hear the classic examples of somebody who is transferred from a care home to a hospital and they are thirsty and no one is aware that they are thirsty or they suddenly ...

Ms. C. Keenan:

That is right, because they do not know how to express themselves, but if you had a dementia liaison nurse they could liaise with the home and you could say how these particular ... that particular resident expresses themselves, how you can tell if they are thirsty, how, you know, what they like to eat, all that sort of thing that the resident themselves cannot express.

Ms. M. Byrne:

We will try, when they go in, we will ... we have got a special form that we send in and we will say, you know, like this person does not like gravy on their food, or they are much better with finger food, i.e. they will not cope very well with a knife and fork, it is much better if you give them sandwiches or like chips and ham, and that way they will be encouraged to eat.

Deputy A. Breckon:

Yes. I was going to ask you about that, because we have seen a report about 3 weeks ago where they spoke to the clients and established an individual care plan so, you know, it was known that you would rather be called Mrs. Byrne than Mary, so that was established well, that people could do that. Are you at that sort of level?

Ms. M. Byrne:

We are. We have to. The inspector will come and look through all our records and if we have not got care plans for that person then they will say: "How are you delivering

care to this person? I need to see how you are giving their care", so we have to have care plans.

Ms. C. Keenan:

All care that we do follows current legislation, both U.K. and local and all best practice measures.

Deputy A. Breckon:

So you might know, for example, that somebody likes to watch Coronation Street, that sort of thing, so you go into that sort of detail?

Ms. C. Keenan:

Yes. A typical example, we have got a gentleman that before he started suffering from dementia was a big football fanatic, so we made sure yesterday that we knew he would want to watch the football, so he had his supper in his bedroom, so he was ready to watch the football. You know, that sort of thing. It sounds like ...

Ms. M. Byrne:

I mean, yes, he might walk out half way through it but we know that we have done all we can, that it is there, that he can watch it if he wants.

Professor J. Forder:

Can I pick up on that, as we were talking about regulation? Is the regulator geared up around some of the newer observational techniques for assessing dementia?

Ms. C. Keenan:

Dementia care mapping, that sort of thing, they have got that in place at the Poplars and you can have dementia care mapping social workers will come out and that sort of thing.

Ms. M. Byrne:

They are usually telling us about things that are probably going to be coming forward long before we know about them, or we might have sort of read about little bits and they are usually quite hot on ...

Ms. C. Keenan:

Yes, they are very good.

Professor J. Forder:

Is that the Poplars or the ...?

Ms. C. Keenan:

The Elderly Mental Health Care team, you know, they are based at the Poplars but they deal with all the elderly mental health issues.

Ms. M. Byrne:

Christine Blackwood as well, you know, who is in charge of the inspectorate, they are always very up on what we should be following and ...

Professor J. Forder:

Are you broadly happy with your relationship with the inspection process?

Ms. C. Keenan:

I think it is brilliant, I have got no qualms with being inspected and making sure that we are up to standard and I think it is a good thing. I do feel, however, that the service should be transparent and so that the same standards, you know, across the board, public and private sector and that the public sector should be inspected as well by an independent board.

Deputy R.G. Le Hérissier:

It is probably about to happen, is it not? There has been a report ...

Ms. C. Keenan:

Quite often, and I speak from our point of view, we feel sort of second class, that you know: "Well, they are only a care home" and we do not get phoned up. Another example is a lady who went into hospital after a fall and the family were phoned up to say she was not eating well. If they had phoned us we could have given even more detail than we had on the form, it is just like: "They are care homes", you know, they

do not ... the sort of transparency across the board is not there. It needs to be one system, not 2 separate systems.

Professor J. Forder:

Yes. I understand. It is also the case that I believe that the inspection reports are not public documents?

Ms. C. Keenan:

No, they should be. From within my owner, the owner that owns our home, if I want to look at any of his U.K. homes I can go on the website and see the inspection forms.

Professor J. Forder:

You would like that system here?

Ms. C. Keenan:

So long as they do not put in things like they do at the moment about light bulbs out and 2 light bulbs missing, which is not relevant with dementia care.

Deputy S. Power:

I think you will find that is one of Mrs. Blackwood's hot spots because you are not the only home she does that to.

Ms. M. Byrne:

She is very approachable.

Ms. C. Keenan:

She is very approachable, she gives good sound advice and I think it is needed but I think it is needed across the board.

Ms. M. Byrne:

In fact, Carol, one of the new inspectors is home inspecting as we speak.

Professor J. Forder:

But I mean certainly in the U.K. there has been a move to so-called lighter touch regulation, which is much less about ticking the boxes and getting out the tape measure and counting how many light bulbs work or not, but much more around the wellbeing of the service user.

Ms. C. Keenan:
That is okay, but I think you need internal audits as well. You know, if you had a lighter touch, say an annual inspection, I think then that you would have to prove that you do internal audits as well in order to ensure that you are complying with all the standards and things like that.

Professor J. Forder:
Yes. Well, I mean there are systems where you might have an inspection holiday if your previous inspection record is excellent, but then you might not get inspected even for a couple of years.

Ms. C. Keenan:
That is right.

Ms. M. Byrne:
I think that would be good so long as they still sort of popped in, so maybe not doing an inspection but just making sure that everything ... because things can slip.

Professor J. Forder:
Sure.

Ms. C. Keenan:
They are not looked on like as the big bad inspectors, they are there ... there is many a time when I will phone Mrs. Blackwood up for advice or, you know: “Have you heard any new legislation?” or, you know, things like that. But ...

Ms. M. Byrne:
I mean, you do dread inspections in a way but you know that they are there for a good reason and I think the level of care over here seems ... we do not seem to hear the

horror stories like they do in the U.K. and I know we are a smaller number but I think it is because they keep on top. They are very hot on making sure that we keep up to a good standard.

Deputy S. Power:

I think the inspection system in the Island has probably learned from one or 2 particular specific examples quite some time ago, and as a result the level of care as a result has become better.

Ms. C. Keenan:

Yes.

Deputy R.G. Le Hérissier:

There is not only for dementia homes but we have sometimes heard from the smaller homes that the regulation can be very expensive and as you know for some of them it has often been: "Is it worth selling the home for property development" or: "Is it worth installing all these individual valves on the taps?" and so forth. Have you ever felt it has been a heavy burden?

Ms. C. Keenan:

Sorry? Like in order to comply with the standards you have to fit the valves, that is a different ... training is a big issue, but as I have said, both Mary and I are N.V.Q. assessors. I am in the process of doing an internal verifiers award so that we can assess and verify a small group of homes, like ourselves, Pinewood, Little Sisters have formed a little group so we can do it for nothing, basically. But that means that the likes of Mary, I, other assessors and verifiers are putting in 80 and 100 hours a week in order to train staff at virtually zero cost. Because if you use the hospital system you are talking nearly £3,000 per candidate and you get them trained and then they are poached. So this way we have to put the time in but then we get the candidate at the end of it, so training is a big, big cost.

Professor J. Forder:

Would you like to see in fact ... I mean there are some examples where the States make financial contributions towards training costs, and it helps ...

Ms. C. Keenan:

Like they used to do, have a grant system, and then if that person leaves they have to pay a certain amount back, you know, Tech used to do it years ago and that would be more beneficial, I think. Because it does come back to the assessors and verifiers putting lots of hours in in their private time.

Professor J. Forder:

Yes. I mean, I think there is this view that the skill mix in care homes involves not so much in your home which is more specialised but in residential care homes more generally the skill mix is still pretty low and that care assistants are relatively unskilled. Do you think that is an appropriate situation or do you feel that there is a need to increase skill levels?

Ms. C. Keenan:

There is a definite need to increase skill levels and I think the more skilled you get, you know, the better service you will have. I think you need varied skills as well, different levels and learning on the job as it were, I think is so beneficial.

Ms. M. Byrne:

I think over here we are a much better skill level than the U.K.

Ms. C. Keenan:

We do ... training is a big issue within the private sector as well and ...

Ms. M. Byrne:

I mean when ... we have meetings with the Care Federation and one of the big things is training and everybody is aware that, you know, that we have to train and that it is becoming more important and in fact sometimes you feel as though that is all you are trying to cope with is the training.

Ms. C. Keenan:

But as I say, that is where the big costing comes in, and that is, you know, the main issue of ...

Deputy S. Power:

Can I just ask a question on training? Like a lot of the other residential and care homes on the Island I am sure you have to employ people who are not native English speakers. Does that present a particular challenge in training?

Ms. C. Keenan:

Sometimes, but we try and get our base, you know, the base there and then if you have got a good sound workforce you can afford to bring in people and train them up. Like I have got 2 girls who are going on a course. They speak perfect English but they cannot write it. So they are going on a course that ... I have forgotten who the provider is for that course, but they are going in September, they start it, to learn how to write English.

Deputy S. Power:

So when you say they speak good English, they cannot write it. Can they read it?

Ms. C. Keenan:

No, but they will learn to read and write in this ...

Deputy S. Power:

So they cannot read or write English?

Ms. C. Keenan:

No, but they can speak.

Ms. M. Byrne:

They can read and write, but just not very well in English. But we do not see why that should stop them coming and working in a care setting, so long as their ... they are only sort of basic, so you have got trainers ...

Ms. C. Keenan:

If you have got trainers and an assessor you can still carry out training with them. You can use dictaphones, you can hold discussions with them and it still proves that they are meeting the criteria.

Deputy S. Power:

So you do not have any other non-native English speakers at the moment?

Ms. M. Byrne:

We do. But their level of English, both reading and writing ...

Ms. C. Keenan:

Their education level is excellent.

Ms. C. Keenan:

Excellent standard.

Ms. M. Byrne:

In fact we have got one girl at the moment who is just starting on a level 3, number 2, level 3, because her understanding and everything is so good that she will not have any problems with it.

Deputy R.G. Le Hérissier:

On the ... I think we have briefly discussed this, but from your observations of how the Island deals with dementia, Carol and Mary, how could we do a better job within the community? What do you think needs to be done within the community?

Ms. C. Keenan:

I will give you an example of things that we do within the community and I think if every home did that then it would help. We get the W.I. come in, St. Martin's W.I. come into us on a Monday. They have a meeting there with their W.I., they have coffee and they do crafts, so you might have one member will be sewing, one will be knitting, one will be making cards, they will all be having coffee and our residents sit with them and they know the members of St. Martin's W.I. Our local church comes in to sing, we go to the local church, St. Martin's School come in and visit and give us

paintings and things and I think the voluntary sector and the community as a base, we can bring the community to us but we can go out to the community and I think, you know, that reduces the stigma as well, you know.

Deputy S. Power:
So this linkage between Ronceray and the community is vital?

Ms. C. Keenan:
Yes. I was talking to the lady that runs the W.I. on Monday when she was there and she said when they started a lot of the members did not like to come because it was a: "There for the grace of God go I" type of thing, you know, they kept away, but as they kept coming and they were encouraged to come, they come all the time because that stigma has been reduced and they respect our residents as normal people that, you know, someone's mum, someone's dad.

Deputy A. Breckon:
Do you come across any levels of hardship and how do you deal with it?

Ms. C. Keenan:
Do you mean financial hardship?

Deputy A. Breckon:
Yes.

Ms. M. Byrne:
Because we are at the sort of slightly lower scale we are quite happy to take people who have run out of money and need to be funded. It ... Income Support now, as it is becoming, we are lucky in that we will still allow them to stay and we have always done that. The home has always done that.

Deputy A. Breckon:
Is the Income Support thing working okay? How does that work?

Ms. C. Keenan:

It has still got its teething problems, but I think once it is up and running ...

Ms. M. Byrne:

I think, yes, it is still very muddled. People do not know where to go, what to do. We still get mixed messages about who ... it is better now.

Deputy S. Power:

If you were to summarise the first 6 months of Income Support or almost 6 months what would be the repetitive niggles and issues that you have to deal with? Take your time.

Ms. M. Byrne:

I mean one lady we have got who looks after her mother's affairs, and she went up, filled the leaflet, the book out, went and took it up to Social Security, took in bank statements and everything, because of course they look through all your financial records and what have you, and then when she tried to find out how it was going on, nobody knew anything about it. That seems to be ...

Ms. C. Keenan:

I phoned on her behalf and nobody had ever heard of her, and I am thinking ... so the daughter had to go back in again which was very stressful and I am saying: "Do not worry, the funds will come through, you do not have to pay, just do not worry about it", trying to reassure the family that funds would come eventually, but they were getting het up in case we asked them to leave but, you know, just a natural progression for them, and in the end finally after 3 more visits to Social Security they got the funding and we had the letter to say it was ...

Deputy S. Power:

Did they retrospectively pay you, then?

Ms. C. Keenan:

Yes, they put it into ...

Deputy S. Power:

Of your 20 beds, how many would be paid for privately by the families and how many would be in that area?

Ms. C. Keenan:

I have got 2 that are still on parish funded, on the old system, and there are 3 residents are on the old system through the ... through the ... have paid through the health pay, through the BACS system and then there are 3 more that are funded from Social Security, so 50 per cent.

Deputy S. Power:

You say 2 are still on the old parish system? That is one particular parish or 2?

Ms. C. Keenan:

One is St. Lawrence and one is St. Clement.

Deputy S. Power:

They are paying you still for ...?

Ms. C. Keenan:

Yes.

Deputy R.G. Le Hérissier:

Is Social Security paying the money through the parish, is it?

Ms. C. Keenan:

I do not know, to be honest. All I know is I have to invoice the parishes and keep them on BACS

Deputy R.G. Le Hérissier:

They get the cheque from Social Security?

Ms. C. Keenan:

I do not know, to be honest.

Deputy R.G. Le Hérissier:

So it is about 50/50?

Deputy A. Breckon:

Something that has been mentioned to us is that perhaps there should be an insurance. Basically, you know, we all pay something in and it is ring-fenced for this, which takes away ... do you think that would be a good idea?

Ms. C. Keenan:

I think it would be an excellent idea.

Ms. M. Byrne:

People get very upset if they feel they have got to sell their houses, which you can understand because the ... you know, the older generation feel that that house is for their families. I mean, my parents are in their 70s, they are not local and they say they keep remortgaging their house. I say: "Fine, that is your money, do with it as you please", but they are sort of very young thinking that way. A lot of older people get very upset when they feel that their house might have to be sold just so that they can be looked after.

Deputy S. Power:

There are a lot of people out there who are asset rich, cash poor.

Ms. M. Byrne:

Yes, very much so. They are using all their assets now, so when they go into homes there will be nothing there. I mean, the bank will own the home, so ...

Deputy R.G. Le Hérissier:

Do you have many clients or patients who have been rejected by their families or do they all generally have family support of one kind or another?

Ms. C. Keenan:

Some do. Varying degrees. Varying degrees, but then again that ... it can be down to not stigma as such but they do not know how to deal with it.

Ms. M. Byrne:

They tend to lose their social skills, you see, when they get dementia.

Ms. C. Keenan:

"That is not my mum", and I must admit from a personal point of view when my mum had it I felt exactly the same: "That is not my mum, why is she doing that?" and you can see that they distance themselves because ... it is not because they want to but they have lost the person they knew as their mum or as their dad, so that ... yes, so that is sort of hard to, you know, bring the barrier, but we try to encourage them to come in and we have sort of family events, like Christmas, Easter, summer barbeques, that sort of thing, to try and encourage them to come in as a group.

Ms. M. Byrne:

Or we will sit with them, if they find it difficult conversing with their relative, then we can sit and help, so you sort of talk around the person and they can pick and choose when they want to come in, to help them feel more at ease, because they are as much our responsibility as the resident, we feel.

Deputy S. Power:

That is why I asked the earlier question about respite, because sometimes it can be so exasperating.

Ms. M. Byrne:

It can be very intense, looking after somebody with dementia. I do not know how people manage at home, I really do not. We can walk away at the end of the day and go home and have a good night's sleep. You look at our residents and sometimes it is 2.00 a.m. or 3.00 a.m. before they will go to bed and they will wake up at 4.00 a.m. or 5.00 a.m. You cannot do that if you are giving 24-hour care. We can because we can go home at the end of the day, because you have different people coming in at night. How people manage at home, I really do not ...

Deputy S. Power:

I looked at a particular case recently, because I am a Deputy, where a lady has a husband who is apparently in the early stages of this where she is getting exasperated and shouting at him. He is getting angry because he does not know why suddenly she is shouting at him because he has made a cup of tea in a glass or he has put something in the wrong place or all sorts of ... he goes out in the rain without a coat, or he is found halfway up Five Mile Road and it is really difficult.

Ms. M. Byrne:
It is, it is very difficult.

Deputy S. Power:
That is why I asked the question earlier. It is a specific set of skills that you need to care for that.

Ms. C. Keenan:
For that certain person that would be nice if they had somewhere where they could say: "Well, I need to go and do my shopping on a Monday, I will get my wife to have lunch with the residents for the afternoon or the morning." That would give them that bit of respite to go and do what they have to do.

Ms. M. Byrne:
Unfortunately I can see it becoming more and more of a problem with the way the Income Support has gone, in that they are losing the attendance allowance where perhaps they could afford to have somebody to come in and sit with their relatives, it has gone to such a low rate that that is not going to happen. So perhaps there is going to be a lot more need for a lot more respite care and day centres that will take people with dementia.

Professor J. Forder:
Can I pick up on that point about attendance allowance? Because my understanding is not that clear on it, so I was really probing for you to explain, because it strikes me that attendance allowance being ... presumably was a more universally available source of funding for people within the community to provide or to allow them to fund those sort of very ... those types of care that you have been talking about,

allowance or respite or some home care and so that money is now being reduced and some of it diverted into the Social Security spot.

Ms. M. Byrne:

I mean I know a lady and she does not have dementia, it is physical disabilities and I mean she has to have a nurse to get her up, she has to have help quite a lot but lives an independent life, because she works still. She is losing ... going to lose her attendance allowance but she still has to pay for nurses to come in and do these things for her that she can no longer do for herself and that is going to escalate and it is certainly going to apply to people with dementia as well.

Professor J. Forder:

So Family Nursing and Home Care would not step in?

Ms. C. Keenan:

They do. They help this lady that Mary is talking about, because I also know her, but only at set times. If she wanted to go to the pictures or to an opera house show she could not. She has to be in bed between 7.00 p.m. and 8.00 p.m. because there is no cover, so she pays private carers to go in to put her to bed 2 or 3 times a week so that she can go out and have a social life.

Professor J. Forder:

Yes, so in fact it varies. Someone told me that you have got the core service from Family Nursing but a lot of people top up.

Ms. M. Byrne:

They have to.

Ms. C. Keenan:

That is where they are going to fall, and you might have ... I mean a couple whose wife has got dementia but the husband wants to go and play golf or go to a golfing dinner, and he would have to pay, you know, extra, and I think that is where the service is going to fall down.

Ms. M. Byrne:

I mean Family Nursing Services will go in and do medication, you know, to make things easier. They will put them in special boxes so, you know, that they will not get confused and things like that, but I mean they are getting very pushed to the limit and if more and more of that is going to happen their role is going to have to expand a lot as well.

Deputy S. Power:

If I were to ask you to make I do not suppose a general observation, that is not fair, do you think the system is going to become ... is on overload and is going to get worse? Or do you think the system is coping at the moment?

Ms. C. Keenan:

I think it is coping at the moment and we are more than happy with the States system and the help that we get but I think as the future develops it is going ... we could hit crisis point really.

Deputy S. Power:

Would you like to expand Ronceray to increase your capacity?

Ms. C. Keenan:

Not too much.

Ms. M. Byrne:

We have applied for another 4 beds, but then I would not want to become too big because then you lose that personal touch. I think the small homes can provide a home-from-home atmosphere and you get to know the families as individuals. We are just one big family really and I think if you get too big you become too institutionalised. The work is then task-orientated instead of person-orientated and it is the people that matter, do not worry about the laundry until there is time to do it. People matter and I think the big institutions do not have that homemade approach.

Deputy S. Power:

So smaller units leaving aside the economies of the thing, 20 to 25 beds is about as big as you want to go?

Ms. M. Byrne:

I mean, there are studies from the U.K. that say dementia care must have access to gardens and outside areas and things like that, so if you are too big that is difficult because they get lost. You can put them in a corridor and say: "Right, well there is the door to the garden", but they might not know the way.

Ms. C. Keenan:

Research has proven that a homely atmosphere is better for dementia sufferers.

Professor J. Forder:

It is quite interesting in that ... and it does unfortunately smack of ageism but in the U.K. I am speaking of the average size of a care home for someone, a younger adult with learning disabilities, is 6 places. The average for older people with dementia who sometimes exhibit very similar challenging behaviour and communication problems is about 25, so in the end it is all about money, because the bigger homes have more economies of scale and generally are cheaper to run and it is about quality of care.

Ms. C. Keenan:

I think that is where we are very fortunate in that we have got an employer, albeit he is an English employer and follows English sort of guidelines of income and that, but as long as we provide a good service he is not too bothered about profit margins. Obviously he wants to make a profit because it is a business but he ensures that we keep to a standard and that money is there to improve the standards as necessary, so we are fortunate, very fortunate. But we are the smallest home that will hopefully by the end of the year just be for dementia sufferers and I think there needs to be more smaller homes.

Deputy S. Power:

Specifically for dementia?

Ms. C. Keenan:

Yes.

Ms. M. Byrne:

But also they should not really have to be segregated.

Ms. C. Keenan:

No. To me that ... you know, they need to have dementia homes because you can then have the experienced staff and can give them good quality of home, but on the other hand we are then increasing the stigma, by segregating them.

Ms. M. Byrne:

So you want a balance.

Ms. C. Keenan:

We need to balance, really.

Deputy S. Power:

Do you know the extent, and this is a difficult question, of ... or do the Alzheimer's Society know the extent of people living on their own who have various degrees of dementia, who are still ...

Ms. C. Keenan:

I think they could give you more idea, because they deal more with the respite and they do a Sunday lunch club, where people can just go for Sunday lunch and they would give you more idea of those figures. Dementia is a very hard thing. If you have dementia and you are living with your family all by yourself the chances of you needing residential care are quite high compared to an elderly person who has not got dementia, because people with dementia are more at risk of accidents and scalding themselves and things like that, so cannot be left unattended for long periods, really.

Professor J. Forder:

Yes, supervision rather than personal care, necessarily.

Ms. C. Keenan:

They need supervision, whether at home or in care.

Ms. M. Byrne:

Yes, they go through stages. Yes, you will get the stage where they have to be supervised, they cannot be left to put the kettle on; they will turn the cooker on with nothing in it and things like that. Then they will get to the stage where they cannot even dress themselves in the right order, you know, they will put on a vest over their dress and things like that. It is progressive. It does not stay at one particular point. Dementia itself is quite slow, because their body is getting weaker; they are getting older, so they are slowing down, so it is a slow decay. With Alzheimer's and things like that, it is much more accelerated, so you get that their body is sort of still capable of doing things, like they could walk into town and things like that, but the brain is deteriorating much quicker and it progresses quicker. I mean, with frontal lobe dementia, it is what, 10 years from onset, of diagnosis.

Ms. C. Keenan:

Life expectancy is 10 years.

Professor J. Forder:

Diagnosis to death.

Professor J. Forder:

You know, that is the interesting thing. I mean, as you say, in some respects, people with cognitive impairment, their life expectancy tends to be longer than people with the same level of physical dependency, if you see what I mean, and so you can get a situation where people do need a high level of care for a very long time.

Ms. C. Keenan:

But I think there also needs to be somewhere that specialises for people of the younger age group with dementia. Having a younger lady with 90 year-olds is not right, but there is no placement for her.

Ms. M. Byrne:

I do not know; I think, to be perfectly honest, she has settled in very well.

Ms. C. Keenan:
She has.

Ms. M. Byrne:
It is the right setting for her now. It would not have been 3 years ago, because her dementia is getting to the stage now she likes to go in other people's rooms to find out if there are sweets and things in there. Now, our residents really are sort of quite accepting of that, because it is the sort of thing that they would do, just wander into somebody else's room by mistake. You know, they do not realise. They think it is all theirs. So she is fitting in very well now.

Ms. C. Keenan:
Now.

Ms. M. Byrne:
But before, I mean, she spent years in the mental health side, because there was nowhere for her to go.

Professor J. Forder:
Really?

Ms. C. Keenan:
There is that sort of mid-age bracket, there is nowhere, so that needs to be addressed.

Ms. M. Byrne:
That is probably going to become much more of a problem as well. There is nowhere for these people to go. It is nice having St. Saviours, Orchard House and those, but I mean, those are for hard-core people. If you have people who have sort of shown signs of dementia and that, they do not fit in that sort of setting, and that is probably going to become more of a problem if people are going to get more frontal lobe dementia and things like that.

Deputy R.G. Le Hérissier:

Are there any more? Yes, you have given us an excellent overview. What about you, Carol or Mary, do you have any other comments? If you had a magic wand to improve the dementia service throughout Jersey, what would be your priorities?

Deputy A. Breckon:

On the future even, where do you see it going?

Ms. M. Byrne:

I think one of the big things, as we are finding at the moment, is we used to have community psychiatric nurses coming into the home, because anybody who was referred via Cedar --

Ms. C. Keenan:

Had follow-up too.

Ms. M. Byrne:

-- we have had follow-up. That is stopping, because their workload is getting so big.

Deputy A. Breckon:

Really?

Ms. M. Byrne:

Yes.

Ms. C. Keenan:

They have been audited and everybody that is seen, as they say, to be in safe care, residential care, has been discharged from the service, which we do not mind too much.

Ms. M. Byrne:

The same goes for us, but --

Ms. C. Keenan:

Yes, all of my residents have been discharged from the Poplars team and if their behaviour or their condition deteriorates and I think they should be seen by them, I have to refer back through the G.P., which is fine, because I feel that my staff are well enough trained in dementia care. But in a normal residential care home, staff might not be able to see the signs of dementia and refer back in time before a behaviour trait escalates or an incident happens, but that is through auditing, and again, finances and things.

Deputy R.G. Le Hérissier:
So this is happening across all the care homes?

Ms. C. Keenan:
Yes. But I know that they are so good at the Poplars and the elderly mental health team that I could just phone up and say, you know: "This, this, this" and they would be there to help me with no problem.

Ms. M. Byrne:
But officially, we would have to get them reassessed.

Deputy R.G. Le Hérissier:
Reapply via the G.P.

Professor J. Forder:
But I mean, again, certainly in the U.K., most care homes, and including just residentially registered care homes, have generally high levels of people with mild levels of cognitive impairment. Is that the case here? Do you think that most residential homes --

Ms. M. Byrne:
Most residential homes will have a degree of people with mild dementia, yes.

Professor J. Forder:
You know, in the sense that they are not that well geared up to or trained to cope with people whose dementia might progress, do you think that is an issue, or --

Ms. M. Byrne:

No, I think that they are getting better. The Alzheimer's Society do --

Ms. C. Keenan:

The services are there for them to refer if need be, you know, if they feel they do need to be referred, but then that just shows that if we are saying every residential home in Jersey has a percentage of dementia sufferers, where will they go when their condition requires E.M.I. units? There is going to be a big --

Ms. M. Byrne:

I mean, the big thing is wandering, you know, but you do not want to stop them walking around and wandering around the home. I mean, we have a locked door policy at the moment, because we want them to feel free to wander around the home, to wander in the garden, to go where they want. We just do not want them leaving the building, you know?

Ms. C. Keenan:

Whereas residential homes, they are open door policies. I mean, our visitors can come in. Our visitors know the key lock and the numbers to get in, but it just prevents the residents wandering and putting themselves at risk.

Ms. M. Byrne:

I mean, we will take them out. I mean, it is not a question that they cannot leave the building. It is just, you know, you do not want them walking on to the main road.

Ms. C. Keenan:

Just unsupervised, unsupervised.

Ms. M. Byrne:

Yes.

Professor J. Forder:

Just one last thing.

Deputy R.G. Le Hérissier:

Yes, carry on.

Professor J. Forder:

This is because I do not really understand the disease that well - obviously you do - I mean, is your job more about the kind of maintenance and coping with people's symptoms or can you have a substantive positive effect on the course of someone's life, where they are suffering from dementia?

Ms. C. Keenan:

You cannot improve their condition. Their condition is going to deteriorate, but you can enhance their life by providing routines and cater activities to their needs. You can just enhance their quality of life.

Ms. M. Byrne:

I think one of the big key things is not deskilling them. They lose their social skills, their niceties anyway. You do not want to be doing everything for them. I mean, a lot of people that come into a home in the beginning: "No, you have to do that for me. That is what we pay you to do." But you are doing them a disservice by doing that, so we still encourage them.

Ms. C. Keenan:

Still encourage them.

Ms. M. Byrne:

If they can still wash their hands and their face, if you have to put the flannel in their hands, then you do that. You do not just go in there and say: "Right, I am going to give you a wash."

Ms. C. Keenan:

Another thing about being small as well is we can keep their skills, like ladies who are used to peeling potatoes every day and things like that, we are small, we can do that. Our ladies peel the carrots for the next day; they peel the potatoes for the next day.

Ms. M. Byrne:

If they want to.

Ms. C. Keenan:

They make cakes. In the bigger homes, where you have 3, 4 chefs, they will not have residents in the kitchen. Some of these skills; we have a lady that makes wonderful French apple tarts, but they cannot do that in some of the bigger places, because the building does not allow for that type of thing, so I think smaller homes are preferable.

Deputy R.G. Le Hérissier:

Well, I think you have given us an excellent review.

Deputy A. Breckon:

Yes, well done.

Deputy R.G. Le Hérissier:

Small is indeed beautiful, I think you have definitely proved in that case, even though the economics are harder and harder in the sector. We all know - as you know from the shop up the road - it is simply easier to sell it and get your property dividend, sadly. Yes, you are lucky you --

Ms. M. Byrne:

It is too far now to walk our residents down to the one by the church, but we are going to do it.

Deputy R.G. Le Hérissier:

I know, I know. Well, put in a protest. Anyway, thank you very much. It has really been an eye opener.

Deputy A. Breckon:

It has been an eye opener.

Deputy R.G. Le Hérissier:

Yes, thank you very much indeed, and if there is anything else you may have forgotten or you wish to say, please get hold of Malcolm and Charlie, and we are always open.

Deputy A. Breckon:
The reason that was recorded is so that we can remember, but it is not to trap anybody or anything like that.

Deputy R.G. Le Hérissier:
Yes, plus our memory is a bit --

Ms. C. Keenan:
Yes, I think that happens with everybody, does it not?

Deputy A. Breckon:
You will get a copy of that.

Deputy R.G. Le Hérissier:
Okay. Thank you very much indeed.