# STATES OF JERSEY

## Health, Social Security and Housing Panel
## Long Term Care of the Elderly

## WEDNESDAY, 30th JULY 2008

**Panel:**
Deputy A. Breckon of St. Saviour (Chairman)
Deputy R.G. Le Hérissier of St. Saviour
Mr. J. Forder (Adviser)

**Witnesses:**
Mr. M. Tomkinson (Alzheimer's Society)

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

I would like to welcome you here to this formal session. I am not sure if you have attended a Scrutiny before but we used to read out a formal caution, so to speak, but the essence of it is that you are here on a privilege, as long as you do not sort of knowingly make comments about individuals that could be seen as, you know, malicious.

**Mr. M. Tomkinson:**

Sure.

**Deputy R.G. Le Hérissier:**

But obviously we want you to speak as openly as possible about your views on the system and on the future of the area in which you are concerned. So, I am Roy Le Hérissier.

**Deputy A. Breckon of St. Saviour (Chairman):**

Alan Breckon.

**Mr. J. Forder (Adviser):**

Julien Forder.

**Mr. C. Ahier:**

Charlie Ahier.

**Mr. M. Orbell:**

Malcolm Orbell.

**Deputy R.G. Le Hérissier:**

Apologies from Deputy Martin who has got called out and is very busy at the moment but will be with us later in the day, and Deputy Power who is away at the moment. Okay, thank you, Mike, for -- we have got a copy of a letter you have sent to Senator Shenton which is a sort of a background letter but we will only sort of keep it in the background.

**Mr. M. Tomkinson:**

Sure.

**Deputy R.G. Le Hérissier:**

What we thought we would start off with, Mike, is basically hearing from you, first of all because you will be of interest to people like Julien, just give us a quick snapshot of your background, both pre and post Alzheimer's Society, and then if you could tell us briefly about the Society, and then we will launch into the bigger policy issues.

**Mr. M. Tomkinson:**

Sure. I originally, when I had a proper job, used to be a biochemist and used to run part of the pathology lab in a hospital in England, the biochemistry lab, and then for about 17 years in Jersey. I then moved on to become a hospital manager, initially in general acute services, and then for several years managing services for the elderly people; and for the last few years Acting Director for Community and Social Services. I maintained an interest in the care of elderly people, and particularly people with dementia. In the local branch we have got a committee of about 9 people, and we try and provide a few services. We provide day care on a Saturday morning for about 15 to 20 people with dementia, primarily to give their carers a break and a bit of respite.

**Deputy R.G. Le Hérissier:**

Yes.

**Mr. M. Tomkinson:**

We provide a helpline where we provide advice. The Alzheimer's Society nationally has an enormous wealth of information on the Internet and we have lots of contacts. So we can provide advice and we tend to know, because of our background, the local systems and can help people obtain services. So we will provide advice, a helpline. We have what we call a Friendship Group where we have carers meeting together and try and provide them with advice. For example, we had someone talking about anger management one week, and we have people talking about the law and how you deal with people's finances, and how you hope to try and retain your assets in the current environment if you have got someone with dementia. We also provide some training for staff in private residential homes, and we are expanding that and having someone trained locally so that they can teach people, not only in private residential homes but we hope in some of the Health and Social Services establishments how to care for people with dementia and memory problems. So I think that is the major role. We provide newsletters and we go out and see people, and just provide advice.

**Deputy R.G. Le Hérissier:**

Thank you, Mike, that is excellent. Well, I wonder if we could move to, I suppose, the big question. You can answer it either as in one whole or bite sized chunks. Like a lot of the questions in these sessions we tend to come back to them, so do not be bothered if you want to bring up other material later. But can you give us your analysis of dementia services provided on the Island, and what you think the strengths and weaknesses are of the current situation?

**Mr. M. Tomkinson:**

Well, I think I would like to refer briefly to the National Audit Office report which is mentioned in the letter I sent to the Senator, because this really is a Scrutiny Report from my perspective, and identifies significant weaknesses and how the N.H.S. (National Health Service) is failing people with dementia. I do not have any evidence that there is any difference really in Jersey. The systems are the same. The people are trained in the same way. There are the same attitudes. So I think if we look at the problems that exist in this document they exist in Jersey as well. I can go into more detail if you would like?

**Deputy R.G. Le Hérissier:**

If you could just sort of elaborate on what you see as the key problems, yes.

**Mr. M. Tomkinson:**

One of the key issues is people are not being diagnosed early, and there is a real advantage in early diagnosis because it helps the family prepare. It means that people can make arrangements and get support, and that support can help them stay longer in their own homes and maintain their independence. A significant number of doctors and nurses in the U.K. (United Kingdom) identified that they really did not have the skills, to diagnose memory problems or to look after people, and I think that that applies in Jersey. I think the General Hospital, and again I refer to another report which identifies the problems, by the Royal College of Psychiatrists, called *Who Cares Wins*, identifies the problems that older people experience if they have got memory problems and are in general acute hospitals. There is a lot of anecdotal evidence - I think some of your colleagues in the States have been contacted by relatives who have said their mum or dad has not been fed properly because the nursing staff are busy; that people often become incontinent because the ward is busy and they are a long way away from the toilet; and that generally they are confused and they are not supported in that environment. I do not think things are any better here than they are in the rest of the U.K. So that covers really some of the areas. I suppose, to move on, a more recent report called *Home from Home* identifies that two-thirds of people living in care homes have dementia, and we like to sort of categorise people and put them in nice little boxes. But a lot of people who are over 80 have memory problems and there is a real need for an improvement in the skill level of people who are looking after old people in any residential setting in any care home. That is not the case in the U.K. and I do not think it is the case in Jersey either, so the real need is to provide training, and that is one of the reasons that, as a Society, we are going to try and offer that to local residential homes to try and improve the standards. I suppose one of the disappointments is that -- I have my original correspondence with the Minister last November, and I met with him within a few days and he expressed concern, and suggested that I and the Society could have a look at the New Dimension document. I still have not had that which is a disappointment.

**Deputy R.G. Le Hérissier:**
New Directions?

**Mr. M. Tomkinson:**
New Directions, yes, sorry. As a consequence of that I circulated my correspondence to other States Members, and I had an interesting response, a supportive response. I suppose what I would like to see is some acknowledgement from the Government that it is not the best service for people with dementia in lots of ways. As they are failing in other countries we are failing in Jersey. At least acknowledge that we are not doing very well and start doing something about it. Now since that correspondence - the U.K. Department of Health have actually moved and they have now produced, together with people like the Alzheimer's Society, the consultation document on the national dementia strategy. The document is here which I can leave. You may well have a copy. I think that we ought to acknowledge that things are not very good and take this on board, identify who is accountable for these sort of services and try and improve things. Perhaps, importantly, let us monitor what happens. Let us have some external monitoring, and let us have some evidence-based information that we are doing things better.

**Deputy R.G. Le Hérissier:**
You have given us possibly somewhat a depressing picture there where it appears we are not up to speed. If you were given the task of reforming the system, Mike, where do you think you would start? What would be your key priorities?

**Mr. M. Tomkinson:**
I think the important thing is to try and do things better, I think this is acknowledged by general practitioners and nurses. I think providing training will be important; I think training for early diagnosis. I think there has got to be some effort to try and increase the support for people in the community. What seems to be happening now is Health and Social Services are making arguments partly for increased funding on the basis of the ageing population. I talked to people in Health before I came to this

meeting, asked them for some confirmation really. I got the impression anecdotally from people that when there is a diagnosis made; can I just check this? Local Carers seemed to be suggesting that it is unusual for a support package to be provided of any significance to help people stay in their own homes. It is unusual. They seem to be suggesting that often little support is available until and perhaps as a consequence people have to be admitted into private care, and I think there are more people going directly into private care than there are in other places in the United Kingdom. That is one of the reasons why the National Audit Office Report identified that the cost of caring and treating people with dementia is more than the total cost associated with stroke, heart disease and cancer; the difference being because Health and Social Services are not providing those support packages the costs are being met by families, and to the detriment of their finances. So I think one of the things that is important is early diagnosis, and really to try and provide some support in the community. What I think happens, is that if there is not any more investment in the service, and I do not think there has been that investment in Health and Social Services, and I have an email from a member of staff who I would rather not quote or I am happy to quote off the record to you, who says -- a senior member of staff talking about my discussion about the failure to support people in the community: "I think you sum up the situation well. To date I have seen no recent indication of any intention to invest additional services in health provision for people with dementia. Sufferers and their families do not get a service in most instances from adult social work who pass it back to dementia services." So I think there is real evidence of failure to provide service. I think what happens is, and I think the same happens with family nursing and home care, is if you do not get an increase in staff, but are having more to deal with, the people who would need the service get less. It is the only way you can cope, and I think that is what has happened. To some extent they are getting very little if they have got dementia and they are more or less going straight in to private care. They are bypassing the Health and Social Services system and going straight into private care, and that seems awfully wrong. You know, this is an illness. We are supposed to provide support for it.

**Deputy R.G. Le Hérissier:**

So just to tease out the areas in which the system needs strengthening, Mike, people will generally self refer. They will go to a doctor and say the behaviour is disturbing.

**Mr. M. Tomkinson:**

Yes.

**Deputy R.G. Le Hérissier:**

Okay. Now what happens? You did mention the role of doctors in your earlier comments. Are you satisfied with the role of G.P.s (General Practitioners) as a gatekeeper in terms of diagnosis?

**Mr. M. Tomkinson:**

I think there is evidence ... no, my personal view is I am not. I base that on the survey in the U.K. My recollection of a survey done more than a decade ago of local general practitioners, and I think it was the States Audit Committee or Group, I cannot remember, and the G.P.s in that audit identified that they would like more training. The other evidence really is people who ring our help line and I talk to, or the members of the Alzheimer's Society, who talk to us first about being worried about their mum or dad and we say: "Go and talk to your G.P." come back to us and say: "My G.P. says do not worry, he is just getting old", and this person, without having the expertise, is clearly dementing and causing real problems in the home for the family, so I think general practitioner training is important.

**Deputy R.G. Le Hérissier:**

You also mentioned, and yesterday we did have a delegation from Health; for example we had Dr. Wilson, and we had John Cox from Adult Social Services and we do understand Adult Social Services is only now being developed as a fully fledged service; so just to follow it through, so we have had the G.P. and let us assume that the alarm bells do ring with the G.P., what does he or she do as a result of having got concerned about the situation?

**Mr. M. Tomkinson:**

Well, as I said, often nothing, but if they do they would probably refer -- they would either try and provide some support and advice or refer the patient to Dr. Wilson and the Memory Clinic. Then of course there is a problem of resource. I think Dr. Wilson may well have identified yesterday that the increased investment in her service has been virtually zero over the last 10 years. So they eventually get seen by the Memory Clinic but they do not get a lot of support. The C.P.N's (community psychiatric nurse) frequency of visits is low. There is not the sort of support that is available in other places in other countries. Family Nursing and Home Care do not seem to get involved with people in dementia. There is not the respite for carers. I talked to a carer the other day who had been looking after her husband for quite a while. She never heard that there was any respite.

**Deputy R.G. Le Hérissier:**
Really?

**Mr. M. Tomkinson:**
She just did not know. She had not had a break for weeks and weeks, and she had been offered little support. Now that is not a criticism of Dr. Wilson's service. I think it is an excellent service. It is just they have not got the resources.

**Deputy R.G. Le Hérissier:**
Sorry to tease it out. At what point, Mike, would you go to Social Services for more support. You said that essentially most of Health and Social Services is bypassed, but let us assume somebody knows how the system works. How would Social Services be brought into the picture?

**Mr. M. Tomkinson:**
Well, I think the G.P. might send you in that direction but it would be unlikely. This is my opinion. I think if you approach Social Services personally you will be referred back to Overdale and the C.P.N.s. You just get sent around. One of the major problems that applies is - in an ideal world what you want is a good assessment and a diagnosis - and on the basis of that assessment and diagnosis you ought to be able to be told what you are entitled to, and have some idea. One of our major roles in the Society is telling people how they can get things or that they are available, again this is not a criticism. One of the problems is the competing demands between Health and Social Services. Everybody says that is a great thing. They are integrated. But in a competitive environment Health, I think, tends to win continually. I speak with a background of Social Services so bear that in mind. I might be biased. But it is very

difficult to win against some more exciting health developments, and I think that that has been one of the problems, not just for older people but perhaps for the younger people as well.

**Deputy R.G. Le Hérissier:**

The last thing, then I will get off my pedestal; you mentioned, Mike, and we have seen the development of l'Hermitage and we have seen the possible development that there will be a new dementia unit on the St. Saviour's site. You know that is a promise, and then one or 2 others; why are these people not coming in? Is it just sort of basically because of what you have described? Why are they not coming into the publicly supported residential care system?

**Mr. M. Tomkinson:**

The public residential care system is fairly minimal. It is a couple of wards at St. Saviour's, so there is a very limited provision. With the whole issue of dementia care and housing, I mean, can I just comment on my thoughts on that? I did get some correspondence from Anne Pryke, and went to meet with her to discuss the proposals for housing for the elderly, and I was particularly interested in ... they had a plan to have housing based on the Hartrigg Oaks principle, where people move from their own environment, the housing around, into a sheltered home and then a nursing home as necessary. I was interested in that because that was the original concept of the Limes which did not work at all. The idea was that people in the area around the Limes would get support from Family Nursing and Home Care and would make the transition into the sheltered flats as they became more dependant, and ultimately into the nursing home. It did not work for a variety of reasons. One is that Family Nursing was running the community service, Housing were running the flats and Health the Limes. So it was run by 3 different departments. If there was a vacancy in the Limes we were not going to wait for someone from around St. Helier if someone in St. Brelade needed a bed, and I think the same would happen here. I think there is some real difficulties. In general terms, if I can just take my hat off as Chairman of the Alzheimer's and speak as someone who is 64, I did have some difficulty with the White Paper. Over 55 - you know, I think life is about stages not about ages. I found it, as did some of my peers, quite offensive that suddenly at 55, when you are paying taxes, still contributing to society, often working, you are sort of identified as a group who need to go and live in some sort of ghetto. That is somewhat tongue in cheek but I do think it is a good plan for housing; I think it is a good way for getting people out of bigger houses into smaller places, and freeing up accommodations for families, and that is great. But when you look at the White Paper and the papers they did, most are owner occupiers, and I think they have looked at about 1,800. Ten per cent of those over age 55 would like to consider downsizing but they do not say at what age. The people who would like to downsize, and that is 5,000 people from social housing, 50 per cent of those wanted to downsize. Now those are people who have, to some extent, been socially dependent, and it is not surprising that more of those might want to downsize. But just making the statement that most people over 55 want to go into what is called by the Housing department – ‘sheltered housing’, and the only reason they can justify that is on the basis that Family Nursing and Home Care is available. Well, they go everywhere anyway. So I did not have a lot of enthusiasm for the plans which, I think, have now been approved. What I do think people with dementia need, and people with head injury on occasion, is some assisted living, places where an elderly lady can look after her husband who has got dementia with some really good support. That could be in a flat, like a flat at the Limes, but somewhere where they can go and eat, somewhere where they can get someone to come in and clean. Then perhaps if they have been together for 50 years they can stay together, rather than the lady having to sell her house in order to pay for her husband to go in a private nursing home. Sorry, I will get off my hobby horse.

**Deputy R.G. Le Hérissier:**
No, no, that is very useful. I think we picked up quite a lot, although we had not upfront made this a study of housing provision, Mike, it has become more and more an issue, you know, as to how you deal with a whole continuum of provision, and the nature of housing and the very issues that you have alluded to that were brought up in this debate and not satisfactorily resolved.

**Mr. M. Tomkinson:**
No.

**Deputy R.G. Le Hérissier:**
As you also alluded to. Okay, that is very useful. Thank you, Mike.

**Deputy A. Breckon of St. Saviour:**

I should declare an interest because I declared this in the States debate that I am 55 years and 8 months so we are talking about me so, you know, I said, you know, I should be tethered in a field somewhere as part of this, and I got 2 offers of somewhere to live during that debate, and one was up in St. Ouen. The other thing I should say as well, Roy and I went to the open morning you had about a month ago on a Saturday morning. I think we just missed you, so I got a load of stuff there and it was useful. I spoke to somebody who has got somebody with Alzheimer's in the U.K., and I was able to pass the link on so it meant they could utilise the services in the U.K. But we were appreciative of the staff and Roy liked the cake and biscuits as well, I should add.

**Mr. M. Tomkinson:**

They were pleased to see you there.

**Deputy A. Breckon:**

That is right. Jo Cummins was there. The other thing I think is of interest, you mentioned something about people contacting you with particular problems. I wonder, without sort of identifying anybody, if you could give us a sort of trail of what would happen if I contacted you to say I knew of someone with particular problems. How would you channel that to me getting something to happen?

**Mr. M. Tomkinson:**

It depends on the issue. I mean, just looking at more recent ones, in the last few weeks I suppose, one lady who has been married for 50 years, her husband was diagnosed with dementia, needed to go straight into one of the wards at St. Saviour's and she found that very distressing. They said that he had to stay there, that she should not go and see him for the first couple of days so that he settled down. But when she did go and see him he seemed very docile and she wondered if he had been given some drug. I have identified the Society's concern with staff using drugs to avoid having to spend too much time with ... and she had been told that she could not go and sit in the day room with him by himself, and she was totally distressed. In that case I copied it to the manager for the services, but in fact, before I even needed to take any action, the lady had gone in again and met a nurse who -- she phoned me and said he was brilliant and that everything was resolved and sorted out. I only heard her side of the story. She may not have heard exactly what was being said, she was obviously upset. So that was resolved pretty quickly. The difficult ones are people who are having to sell their property, or downsize, or pay to care for their partner. I mean, it really is so distressing and I do not know what to say to them often. I mean, you know, I sat listening to a lady in tears saying: “But we have lived here all our lives, you know, and I want to be able to, you know, bring him home on occasion” and there is nothing I can say. I mean the need for a Social Security system is so self-evident, is it not?

**Deputy A. Breckon:**
I just wonder if I can go back to the first case you described to us. What happened before the referral to St. Saviour’s? Were the people known to you or not? Would you say the system had failed them?

**Mr. M. Tomkinson:**
No, they were not known to us, and the diagnosis had only been made a few weeks earlier. So it might have been one of these cases where the lady had been told: “Do not worry, he is just getting old.” Do you know what I mean?

**Deputy A. Breckon:**
Yes.

**Mr. M. Tomkinson:**
There are over 1,000 people with some degree of dementia problems in Jersey. A lot of them are not in touch with the Society or their G.P.

**Deputy A. Breckon:**
In your experience as Chairman, from the Society’s point of view, is the number of people contacting you increasing or is it the same, or decreasing or where are you? Do you know?

**Mr. M. Tomkinson:**

People are contacting us more and more. We are getting more telephone calls. It is hard to say whether because there are more people. Statistics would suggest there are because it is an ageing population. It is partly to do with the fact we have been more effective at publicising our services I think but there seems to be more about.

**Deputy A. Breckon:**

Or could it be because people are perhaps frustrated by the system and it is felt then that they coming to you it is a sort of pressure point, if you like, so that you can maybe help them to get whatever it is they are wanting or whatever they want to get to?

**Mr. M. Tomkinson:**

I think you are absolutely right but ... we learn that from what we call our Friendship Group where there are carers there. One of the problems if you are a carer is that you are very vulnerable. You do not want to offend the people who are looking after your partner. That is why health services like the N.H.S. survive really. People are grateful and vulnerable. There is nowhere else you can go. You are frightened that, you know, your partner might suffer if you are a bit difficult with the staff. Just human nature, is it not? So, yes, I think people do find it difficult.

**Deputy A. Breckon:**

What about the services that are available generally? Do you find that there is a coherent structure that you can get people into and they are getting positive outcomes, or is it frustration after frustration?

**Mr. M. Tomkinson:**

I think it is frustration after frustration. I mean we have to look at what services there are for people with dementia. There is the service run by Dr. Wilson which is under-resourced and stretched, and really cannot cope with the numbers. I think Dr. Wilson, I would suspect, has said that to you yesterday, I would be very surprised if she had not. It is self evident, you know. One of the things that is causing difficulty to some extent for the services, when you get a lot of carers together and they hear from each other what they are getting they say: “Well, why can I not have this?” It is not because they are being assessed and it has been decided they do not need it, it is because there is not enough and so the staff I think are giving it to those who need it most.  Some are missing out significantly.

**Deputy R.G. Le Hérissier:**
When you say services are being distributed differentially so to speak, Mike, what services do people get that others for some reason, resource wise, are denied?

**Mr. M. Tomkinson:**
Respite is something that people get; care at St. Saviour’s; visits by C.P.N.s, day care.

**Deputy R.G. Le Hérissier:**
Where would they go for day care?

**Mr. M. Tomkinson:**
Primarily to Overdale for day care.  So those are probably the services that they get.

**Deputy A. Breckon:**
Is staffing a problem, in your opinion?

**Mr. M. Tomkinson:**
Yes, yes.  I mean, I think the staffing levels are far far too low.

**Deputy A. Breckon:**
Is the training and the quality there in the staff?

**Mr. M. Tomkinson:**
I think the training and the quality is good, and I have no criticism of the quality of the service, but I think it is just stretched.

**Deputy A. Breckon:**
It is specialism really so the training and understanding does not generally cross homes and others in the medical profession.

**Mr. M. Tomkinson:**

No, and I think that perhaps reflects health and to some extent social services culture. There is a tendency to put people into boxes. If you are old and confused and got physical problems it is a bit of a problem for clinicians. Which box do they put you in? Shall we send you to a psychiatric ward for old people or shall we put you into a nursing home, you know? They do not like that. So when you move outside the specialist services, yes, I think they are very poor. I think the acute hospital is extremely poor, as all are I suspect. That is not being critical of this one particularly. I went to a national meeting and met with chairmen from around the U.K. talking about acute hospitals in their area, and we all have the same stories, a lot of it anecdotal. Some of your colleagues have been contacted by relatives and been told their stories, and so it is pretty bad in acute hospitals. It is pretty bad in a lot of residential homes. One in 3 people in residential homes have dementia or memory problems. In Health and Social Services residential care how many people in the Limes, Overdale and other places, have the skills to look after people with dementia and memory problems. Some but not enough I do not think, and I think again this report, *Home from Home*, says it all. What is sad is you can save an awful lot of money by getting these services right. You can do things better. I think Deputy Martin wrote to me after my correspondence and said, you know: "Yes, we need to do more, but, you know, there is a lot of different demands", and I acknowledge that, but sometimes just by doing it better you can improve things. I think there are lots of opportunities in this area to do things better. It is going to need more money. It is self-evident but, you know, training would improve things dramatically.

**Deputy A. Breckon:**

Do you think the service needs a peer review rather than a review from people who are already in it?

**Mr. M. Tomkinson:**

If you ask me what I thought the service in Jersey needed, I think it needs a Scrutiny Report. I think these UK reports provide evidence of what is happening in Jersey, and I do not think we need to waste any more time reviewing it and writing strategy documents. I think for God's sake let us get on and do something. I mean, since last November the U.K. have produced this strategy for dementia care, how to improve things. Why do we not take it on board? We do not need peer reviews. Take it on board, agree to do something and then have some external monitoring. Provide some evidence that things are better in Jersey if you can. It is unlikely. Why should it be?

**Deputy A. Breckon:**

The only other thing I was going to say is where are you with age with cases that you are finding? Is it mostly elderly or have you got younger sufferers?

**Mr. M. Tomkinson:**

It is mainly older people. The incidence increases dramatically, I think, over 80, is one in 5 or over 85; but there are a few younger people and it is extremely difficult for people; there are one or 2 in the late 50s, not much older than yourself, and some in their 60s of course, but they are a minority.

**Deputy R.G. Le Hérissier:**

Yes, we did hear about that yesterday and they are posing issues both for Dr. Wilson's team and for residential homes to which they are allocated because they fall between the cracks of the current imperfect services. What I was going to ask you, Mike, I think I was reading a study the other day which was saying if you grow up with certain social indicators, you know, you have grown up in relative poverty, or you have grown up as a heavy smoker or a heavy drinker or whatever, the prognosis for Alzheimer's is quite high, and that we need to start addressing, you know, how we socially manage the situation as well as how we deal with the kind of immediate issues that you have so eloquently described. Do you think that we can refashion our health services to do something from that point of view?

**Mr. M. Tomkinson:**

Yes, I can, and I am to some extent a sort of gatekeeper to poacher, am I not, coming from a health care background, but I did make the argument often that we ought to try and do more than deal with illness. Health and Social Services was originally Health and its business was dealing with people who were ill. It became Social Services without any increased funding. I think the Children's Service joined Health and it suddenly became Health and Social Services, retained a dominant Health culture, and therefore I think has tended to concentrate on those issues. Coming back to what you were saying, without a doubt improving social care can make an enormous difference.

I mean, just looking at the housing survey it is interesting that the people at the moment in social housing want to downsize much more than the people who are socially independent. I mean, that is just an example of the difference. An example which stayed in my mind, and I have to be careful quoting this if it is on record, but I will anyway, is that I remember going to a meeting of Age Concern, and there was talk about employing a cook to provide lunch for these ladies. These ladies who I thought quite enjoyed getting their lunch themselves but it was felt that someone ought to do it for them because they were, in a way, seen as being dependant. The next day I went to work and I met the elderly ladies who were quite older than the ones at Age Concern picking up the boxes to take out Meals on Wheels. Now those people are more independent and contribute more. They also have more money I suppose, so they may tend to be healthier, they may have a better diet; I think we ought to concentrate on all those things. There is evidence that if you are more affluent, well, you certainly are not going to suffer from hypothermia as an extreme example if you have got lots of money. If you go on sunny holidays, eat well, have money to perhaps afford private health care or get health care that you would choose does make a difference.

**Deputy R.G. Le Hérissier:**
Okay, yes, that is very useful. Do you have anything, Julien?

**Mr. J. Forder:**
If I can just pick up on 2 things if I may? Talking about Community Support and particularly the role of Family Nursing in this because I would have thought that this would be an important role for Family Nursing to give social care support to home help, home care support to people with early stages of dementia, mild levels of dementia, and particularly those who are still living on their own, even though those living on their own tend to move very rapidly into a care home setting. It seemed from yesterday’s discussion that Family Nursing did not play a very large role in this or were limited as to how far they could go, and I wanted to hear your views, and you certainly touched on that bit.

**Mr. M. Tomkinson:**

I was not aware that they provided hardly any at all. Certainly, when I was involved they did not. They would say, I suspect, because of the resources that are made available to them that they cannot and as the patients are being seen by the Community Psychiatric Nurses in Health they are getting the support from them, but they are not getting it from anybody.

**Mr. J. Forder:**
Right, okay. The second thing, just to pick up on this issue about new drug therapy for dementia and your views on that, and what the situation is in Jersey, if you have the details, and I am thinking about particularly some of the announcements that N.I.C.E (National Institute for Clinical Excellence) has made about the use of these new treatments.

**Mr. M. Tomkinson:**
Yes. I did have correspondence and discussions with Health when N.I.C.E. made its decisions about the anti-dementia drugs and, in fact, as far as I am aware, the decision whether to prescribe those or not is based on a clinical decision, which I think is quite appropriate. I think Dr. Wilson would not prescribe unless she thought they were going to be of benefit, and as far as I know in Jersey that has been the general principle, that people have not been denied drugs on the basis of decisions been left to a clinical decision.

**Mr. J. Forder:**
Okay, thank you.

**Deputy R.G. Le Hérissier:**
Okay. At an earlier stage we covered New Directions. Well, it was mentioned, Mike, and you have not seen it is what you said.

**Mr. M. Tomkinson:**
No. It was suggested that I would have a copy last November but I have not, no.

**Deputy R.G. Le Hérissier:**

Yes, unfortunately there have been a series of delays which is why rather than scrutinising New Directions we are scrutinising this at the moment, where obviously logically it would have made sense to do the big policy first and then drill down, but we obviously got fed up with waiting around.

**Mr. M. Tomkinson:**
Yes, I mean, just a thought on that, and I speak with a background of being involved in developing strategy; if I had been asked to produce this strategy for dementia in Jersey I suppose I would have had a go, but when I look at the people who and the expertise that has contributed to this (The draft National Dementia Strategy) why bother, you know? Make sure it fits Jersey. You can spend decades trying to produce a strategy in Jersey. You will not get the quality because you do not have the expertise so for God's sake use something like that.

**Deputy R.G. Le Hérissier:**
Here is a leading question. From your experience as someone within the system who has battled for change, if you were advising somebody, well, it could be yourself of course, on how to bring about a change to what you have described as a very under resourced and low priority service what advice would you give them?

**Mr. M. Tomkinson:**
How to, one simple thing, identify who is accountable at different levels. Identify clearly what the Minister is accountable for, identify clearly what the Chief Executives are accountable for, and as you go down the organisation so you can say: "Well, who is responsible for ensuring that people with dementia get a good deal?" Then you can start talking to them and you can start monitoring them. You can have external monitoring. Because if you asked me that question today I would not know where to go. I suppose the Minister.

**Deputy A. Breckon:**
Do you think there is a gap there? Does anybody fill the advocacy role?

**Mr. M. Tomkinson:**
From the public point of view?

**Deputy A. Breckon:**

Well, from the client's point of view, who represents the client? I know, for example, I think Focus on Mental Health have somebody who does the advocacy stuff.

**Mr. M. Tomkinson:**

Yes, they do and in fact we provide advocacy where we can, and I have an agreement with Focus on Mental Health if there was an issue we will --

**Deputy A. Breckon:**

I am a member by the way. I should declare an interest.

**Mr. M. Tomkinson:**

Right. Well, I discussed with Anton Skinner a year or so ago that if there was an issue where we felt that they were more able to help someone they would help us and provide that support. But one of the things is of course people do not know who to go to to get advice.

**Deputy A. Breckon:**

Can you just remind us, where do you get your funding from? You do newsletters and --

**Mr. M. Tomkinson:**

We get it all from contributions and fund raising. We tend to get quite a lot of donations from people over the years. We do not have an enormous amount of funds but we have enough to produce a newsletter, and we have been so lucky. We have just got a small office in the Town Hall and we have got enough money to do a few things we wanted to do. One of them is get a really competent trainer, and secondly we have just advertised for an administrator to work 10 hours a week so we can do a lot more things.

**Deputy A. Breckon:**

Have you applied for any -- you are a registered charity?

**Mr. M. Tomkinson:**

Yes, we are.

**Deputy A. Breckon:**

Do you get anything from the Jersey Charities?

**Mr. M. Tomkinson:**

We do not, and the reason that we have not applied, for what we have wanted to do so far we have managed to get enough funding. I have had donations from a few sources but we are really waiting until we have got some projects. We might even offer to provide some services, particularly in training, and then we would want some funding.

**Deputy A. Breckon:**

Have you ever applied to say Health and Social Services for an annual grant?

**Mr. M. Tomkinson:**

We do get a grant.

**Deputy A. Breckon:**

You get a grant?

**Mr. M. Tomkinson:**

That grant goes towards us providing day care on a Saturday. It does not cover the cost but it helps.

**Deputy R.G. Le Hérissier:**

Yes, we saw that service when we were there.

**Deputy A. Breckon:**

Do you know how much it is?

**Mr. M. Tomkinson:**

Off the top of my head I cannot remember.

**Deputy A. Breckon:**

Fundraising is okay some times for profile but if you have, you know, a focus on your present debt then sometimes you get diverted if you have to have car boot sales and things like that.

**Mr. M. Tomkinson:**

Sure, yes.

**Deputy A. Breckon:**

But it also brings people together so there is, you know, some conflict resource and some good there as well. Do you get anything from the National Society? Are you affiliated to them? Do you pay them or do they give you anything?

**Mr. M. Tomkinson:**

We are a branch of the National Society and on balance we get an enormous amount from them. I mean I have just been to a Regional Conference in Bristol and they paid my flights and accommodation. They send people over to help with training. They provide an enormous amount of advice.

**Deputy A. Breckon:**

Do they get a Government grant, do they, the National Association?

**Mr. M. Tomkinson:**

They do get some money from the Government and they are very involved with the Government, and we are involved with producing the strategy.

**Deputy R.G. Le Hérissier:**

One of the things I suspect will start happening, Mike, is that groups who are involved, like the Parkinson Society would be another obvious one, if there is this real paucity in service they are going to have to get together and push, almost as a federation of care agencies or voluntary groups, and say to the Government: “You have got to get your act together.” Is there any sign that that is going to happen?

**Mr. M. Tomkinson:**

No, I have not seen any sign of that. I know that Parkinson's have worked with M.S. (Multiple Sclerosis) and Motor Neurone Disease on some issues, but more recently I have not heard anything. I think one of the frustrating things when I was talking - and I mentioned it earlier - to people from a couple of other charities, is it is very hard to get people to admit that things are not as good as they should be, and that is irritating because if you cannot do that then where the hell do you go? Do you know what I mean?

**Deputy R.G. Le Hérissier:**

Yes.

**Mr. M. Tomkinson:**

I mean, I know Dr. Wilson will have come here and been quite frank about the strengths and weaknesses and that is refreshing but it is not that common. It is nice to hear.

**Deputy R.G. Le Hérissier:**

Okay. I think we are in the sweeper up phase of the discussion now so I will pick on a couple of random points and ask my colleagues if they have any more. I want to come back to the role of Social Services because I really had the distinct impression that after years of neglect we were moving ahead on Adult Social Services in particular, although I know obviously there are issues on the children's side and I would have hoped that that would have provided, you know, more support for your group. But are you telling us that there has not been a focus on the dementia group from Adult Social Services? Is that the case somewhere?

**Mr. M. Tomkinson:**

I do not think there has been any service from Social Services for people with dementia. I do not think they particularly see it as part of their role. I have not heard anything to the contrary.

**Deputy R.G. Le Hérissier:**

So when a relative does place a loved one in one of the dementia homes, one of the private homes and so forth, there is no referral in order to provide more support to that family is there, for example?

**Mr. M. Tomkinson:**

No, not that I am aware of. No. In fact once the patient is placed in a private nursing home or dementia home I am not sure what they do get from Health or Social Services. I think that takes them out of the equation to a large extent.

**Deputy A. Breckon:**

Can I just ask, Mike, how much do you think there is a stigma attached to Alzheimer's? How much are we generally accepting it? Where are we as a society do you think?

**Mr. M. Tomkinson:**

I think as a society the stigma is significant. I mean, on a personal level, my mother has just come out of hospital, been told that she had a little stroke. She is 85. I know that she has had memory problems for the last 3 years. I have talked to my step father and said: "Look, I think mum is having little strokes." She has got real memory problems. She gave her place of birth in the hospital where she lived when she was 11. Short term memories about -- no one at the hospital mentioned it" My step father said: "Oh, she is just getting old, Mike." I said: "But you could get some help if you have got the diagnosis." He said: "No, I can look after." So in the older generation I think it is a stigma. Jo Cummins and other people were trying to talk to children and try and get them to understand that Gran is not daft, she is just, you know ... and we are trying to change that but without a doubt, you know, it is an illness is it not? It is a deterioration of the brain and really very difficult to cope with.

**Deputy A. Breckon:**

Just to relate something to you. We had somebody who came to see us a couple of weeks ago and their experience was that they wanted the community because their prime aim is for people with dementia, fairly small, under 30 residents, and they asked the local school to come in, and they also asked the Women's Institute. At first there was some, not tension, but there was some nervousness about the situation, and then it was accepted and they felt it was a tremendous benefit for all, people coming in and experiencing and sharing some time with the patients. In your opinion would that be the exception rather than the rule about how society is interacting with groups or individuals with dementia?

**Mr. M. Tomkinson:**
I think we tend to put people into compartments, do we not? I think that that story is great. I remember years ago going to a day care which was being provided for old people with physical and some mental health problems, and there were some children there with physical problems, not major ones, this day care was being run by an Austrian and I said to him: “You know, this is rather bizarre bringing all these people together.” He said: “Well, we should have day care centres for schizophrenics and they can all learn how to be better schizophrenics together.” So the thought of mixing people who have got various needs and getting them to help each other and learn from each other is great, is it not? Do not let us put all old people together in a ghetto without any folks around them.

**Deputy R.G. Le Hérissier:**
Okay, Julien, any wrap up points?

**Mr. J. Forder:**
It is just really this general point about some people regard as different treatment of people with Alzheimer’s from people with other long term health conditions, cancer for example or heart failure, and that some people say that this is primarily because for Alzheimer’s there is little that can be done in the way of actual treatment for the underlying condition, and that the ramifications of having that disease is a personal care need rather than a health care need, and I just wondered what your take on that is. You certainly mentioned the issue about the fairness in regard to people with Alzheimer’s when this is seen as an illness against people with other long term health conditions.

**Mr. M. Tomkinson:**
Health care services tends to sort of opt out of some areas, do they not? I mean, a good example is they are very keen to operate on people with cancer and try and cure

them but if they cannot do much then they leave it to charities like the hospice. I think in some ways ... because they cannot do anything dramatic and cure people with dementia or Alzheimer’s then they tend to lose interest to some extent. Is that fair? I think it is dreadfully unfair. I think it is totally unfair, you know, if you have a heart attack or a stroke you, to a large extent, get supported. If you have Alzheimer’s or dementia you end up getting nothing. It just cannot be right, can it? I mean, it does not make sense. I mean, can you justify that on the basis that you are not going to be able to do a lot? I think you can do a lot. I think you can improve the quality of life enormously. I mean, when you listen to some of the carers, you know. I spoke to a lady who can hardly find time to get to the toilet and leave her husband, you know. Something wrong with the society who is not going to help people like that.

**Mr. J. Forder:**
Yes. The focus on quality of life rather than the necessary length of life which is a medical preoccupation.

**Mr. M. Tomkinson:**
Yes.

**Deputy R.G. Le Hérissier:**
Okay. Thank you very much indeed, Mike. That has been most illuminating, and thank you for your commitment.

**Mr. M. Tomkinson:**
Thank you for the opportunity. Can I leave copies of these?

**Deputy R.G. Le Hérissier:**
Yes. If perchance there is anything you feel when you get out of the room you realise you should have told us and you have not told us obviously we are open to further material. So, thank you very much indeed.

**Mr. M. Tomkinson:**
Okay, well, thanks for the opportunity and best of luck. It is a challenging topic for you all.