

## Notes for Scrutiny: Long Term Care (LTC) Scheme

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These notes have been written by:

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Please note that all names have been changed to protect our clients' identities.

### Introduction

Through my work as a counsellor and family support co-ordinator (CFS) for Jersey Alzheimer's Association (JAA) I have contact with people with dementia, family carers and professional carers. I have a current, active client list of approximately 20 people with dementia and 53 family carers. Further to these people, I have contact with many more people with dementia and family carers through the other services and activities provided by our charity.

Of the family carers who access the services I provide for JAA, more than 90% have wanted to discuss issues or problems they have experienced related to the LTC scheme.

Because our clients were consistently finding the LTC scheme difficult to understand and navigate, and were often quite distressed by this, adding to the difficulties they faced as carers, I made every effort to understand the scheme myself. By so doing I believe I have been in a better position to help and direct them appropriately.

### Professionals' Understanding

I believe that many of the problems our clients experience have arisen because the professionals who have been responsible for communicating the scheme to their clients do not have an adequate understanding of the scheme they are involved in administering.

Of necessity this scheme is complex, making it harder for most people to understand and then communicate to others. I believe it needs to be more rigorously taught to any professional whose work includes this scheme. A common problem for example, is that people are told they need to fill in financial disclosure forms, and go to huge lengths and sometimes expense to do so, when they do not need to if they wish to state that they have assets over the threshold limit and are happy to pay for care costs up to the care cap. Other problems I frequently encounter are with people getting the LTC forms from Social Security, filling these in and then waiting indefinitely to hear from Social Security about the amount to be paid to them for care, when they have not first had an assessment of care needs carried out by a health care professional. The need for this sequence of events is not sometimes understood and/or communicated well.

This week Mr Brown spoke to me, through his tears, about the weight of responsibility he felt burdened by as he was trying to understand the LTC scheme and at the same time help his dad make sound decisions about financing his care.

### Professionals' Communication

Many of our clients say that they receive conflicting answers and information from different professionals (including staff at Social Security and Health and Social Services staff) which then leaves them more confused.

They also say that they do not feel they are able, or given the time, to question professionals about the information they are given that they do not understand.

They say they feel there is a presumption that they will understand new information from the outset. Professionals do not seem to first check what information people already have of systems, benefits and services generally.

They say that professionals often speak too fast and use abbreviations and jargon which they do not understand.

They say that professionals do not check they have understood what they have said and what they then need to do.

### **Public Understanding**

From my work I am aware that people accessing the LTC scheme for a family member are very likely to already be under some considerable stress from their caring role. They may be elderly themselves, may have careers to manage and children too. Finances may be a huge worry alongside uncertainty for the future. Our clients have often voiced their belief that professional staff do not seem sympathetic concerning such issues.

*(Consider the following: Mr Jones cares for his 80 year old wife who has dementia. He has had to pay for a professional carer to look after his wife for 2+ hours at £20 per hour while he goes to Social Security in town to try to find out more. Mrs Jones does not know the carer and is really unhappy being left by her husband. He cannot drive and has a mobility problem. He takes the bus and has to walk from the bus station to the Social Security building using his stick. He then waits in a (standing) queue for 20 minutes only to then find the person he speaks to cannot give him the information he needs (or he later realises he has been given the wrong information) and suggests he comes back again to speak with someone about the LTC scheme. He repeats the trip 3 weeks later when he has saved enough to pay for a carer, but is given the wrong forms. The correct forms are eventually sent to him in the post but they are so complex he gives up trying to fill them in. Mr and Mrs Jones' situations deteriorate. I have heard very many similar accounts.)*

This scheme is not well understood by our clients who seem more confused as a result of receiving conflicting information from professionals.

The documentation related to the LTC scheme is very complex and assumes a high level of comprehension from its readers. (Lawyers, accountants and doctors have asked me for help because they find it so difficult to understand.) I think that a simplified version of the documentation would be very beneficial to supplement this.

I do not believe that enough emphasis is given to this being a new scheme (since July 2014) and that therefore people should be encouraged to discard what they may have understood about the financing of care prior to July 2014. People often come to me very fearful about losing their homes or not having enough money to buy in professional care or for a relative to move to a care home. I believe a renewed effort to promote this as a new scheme would be helpful.

Further, as this is a relatively complex process, I believe that it would be helpful to assign care co-ordinators to people to help them negotiate the process. I am also of the opinion that such co-ordinators, as a single point of contact and information, would help people access other services to meet their varying needs.

People, particularly those who have never needed to access any benefits in the past either from the Parish Welfare scheme or via Social Security, do not often understand that further benefits are possibly available to them, and the reasons why others may not be available. Added to this, I am aware of a general feeling, or sense, from the conversations I have, that people do not believe the benefits system is 'fair' or well managed. Our clients have also frequently expressed the opinion that they feel the States are dishonest by not referring to the LTC charge as a tax.

### **Time Taken to Access the LTC Scheme**

Almost everyone who has spoken to me has told me of delays they have experienced in accessing this scheme. This has often been due to misinformation about the necessary sequence of events as described above, or because documentation or information has been misled by Social Security or for other unknown reasons. Our clients have

described situations where they have been waiting months to hear about the outcome of their application and in the meantime situations have deteriorated so much that crises have occurred that could have possibly been preventable if care had been put in place when needed.

### **Eligibility Criteria**

Most people, with only a few exceptions, accept the eligibility criteria and understand this aspect of the scheme.

Some of our clients have questioned the need to contribute to this scheme in the extra new 'tax' as they believe that care should be available from 'the taxes I have paid all my life'.

Others who question the need for a new 'tax' are more accepting of this when I draw their attention to the scheme being available for people from the age of 18 who have long term care needs, perhaps due to an illness or accident. Perhaps this should be highlighted more as I think many see this only as a scheme set up for elderly care.

I continue to receive enquiries from people planning to bring their elderly parents to Jersey so they can care for them and continue to work here. The need for 10 years residency before accessing the scheme should perhaps be made clearer so people do not make the mistake of moving their parents here and then being unable to afford professional care for them.

### **Approved Providers List**

It is still not well understood that care providers need to be registered for people to claim the cost of care. Some people who speak to me and want to access the LTC scheme are already using care providers who are not registered. These often provide excellent care with which both the person with dementia and relative are happy. When joining the scheme, good, working relationships have had to be lost and costs have increased substantially as a result. Carers have told me that they believe that the increased demand for registered care providers is pushing up both home care and care home costs.

If people do not know how to access the list of approved carers, or cannot access this online, they are disadvantaged. Many still think that Family Nursing and Home Care are the only home care providers in Jersey.

### **Care Available at Home**

Many people tell me that the professionals they employ to care for their relatives do not seem to have appropriate training or skills, especially in caring for a person with dementia.

Some have indicated that the amount of care they need exceeds the budget they have for care within the LTC scheme. Others have indicated that home care providers have different and higher rates for people who are accessing care with the LTC scheme.

### **Care Available in Care Homes and Costs in Care Homes**

Many people tell me that they have had no choice in the care home for their relative as beds are so limited, especially for those needing specialist, secure dementia care units.

They believe this is inflating the prices so that most care homes now charge similar rates even though room 'quality' may vary. Our clients say that the LTC documentation and professionals' do not give an accurate picture, indicating there is more choice and more price options than they believe exist. On occasions our clients have been asked to source cheaper care home options when they are not able to meet the costs of the care home that was initially recommended to them.

Most people, if they have some understanding of the benefits of the LTC scheme, wrongly think that once the care cap is reached (if this is necessary) that they will not have to pay any more towards a relative's stay in a care home. They do not understand that the co-payment and top up charges will still have to be paid. This would mean that for someone living in a care home, even after the care costs have been paid, they might still need to pay £600 per week. This sum eats into any assets a person may have and is often a source of huge worry. Although some allowances are made for the costs of continuing to run a family home for a second person who does not need care and is continuing to live in their own home, this seems to be insufficient.

There seem to be significant problems for people wishing to access temporary, respite care so a carer can have a break from caring while a relative is cared for in a care home, or if the carer needs to go into hospital themselves or becomes too ill to care for a while. Health and Social Services previously administered a respite budget, which was available for such care and allocated at the discretion of a Community Psychiatric Nurse or Social Worker. While this was not always equitable it usually meant that people could access respite when they needed it or if they booked it in advance. Now that respite care is a component of the LTC budget, people have to be in the LTC scheme to access respite care. Often the need for respite is urgent and unplanned and may be necessary for people not yet needing regular, high level care, who have not joined the LTC scheme.

Further to this, our clients report that finding care homes with respite beds is virtually impossible, as increased demand for permanent care home beds has limited the number that care homes keep for respite only. Obviously, as a business it is easier to have a room permanently occupied with revenue thus maintained, as the room is never unoccupied.

### **Current Assistance Available to Carers**

Carers frequently report to me that they feel uncared for by 'the system' and that the only support they feel they have available to them is provided by JAA. There seems to be no provision in the LTC scheme for carers, apart from the (problematic) respite component described above.

### **Property Loan Process**

So far no one has reported any problems to me regarding the property loan process but people have been pleased that this option is available to help protect their property and the need to sell it to pay for care.

### **In Summary**

I believe that for as long as care is provided by businesses and while this is limited, prices for care will continue to rise and the quality of care delivered may be increasingly difficult to regulate.

Further to this I believe that regulating the quality of care given to people may be increasingly difficult, particularly as these businesses often deliver their own training and often pay the minimum or low wages for carers. Our clients report that staff turnover appears high, which may increase. If it does this may further limit the continuity of care and affect relationships made between the person being cared for and the professional carer. This makes it increasingly difficult to maintain communities of person-centred practice.

Because of this I believe that a review of the methods used to establish standard care costs and co-payments and top up charges is necessary.

While I believe that the LTC scheme is mostly excellent, I am of the opinion that the people responsible for its delivery and administration have not been adequately trained in it and in its delivery to the public. The public have not been well prepared for this new scheme and have been further confused by professionals who have misunderstood it and then miscommunicated it to them.

From my work with very many people over the two and a half years of the LTC scheme's operation, I believe that it is possible to communicate its complexities well and then nurture people through the process of application successfully.

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