

## Health and Social Security Scrutiny Panel

### Long-Term Care Scheme Review

Written Submissions

#### **Submission 2:**

I've been quite blue today thinking about this time of my life, but I feel it needs reporting if there is any possibility of improvement in the system.

My father passed away June 2015, aged 79yrs, after 15 years of gradual decline. For the last four years he was doubly incontinent and increasingly restricted mobility, with about three urine infections each year requiring hospitalisation.

At his best he would hobble along with a zimmer frame.

My mum, 3 years older than him was forced to be his main carer.

They were hotel managers for the majority of their working life. Not well paid, but frugal, and after 35 years working, owned their own house. They fell under the annual income threshold in their retirement to pay tax (£22k?)

Family nursing would come in every day to put my dad to bed, and we organised two qualified carers directly, not through an agency, to get him up, showered and dressed each morning. Towards the end of his time at home, they would also come at lunch time to toilet him.

We saved a lot of money by organising the carers directly and not through an agency.

One of the main problems was that mum, at 80years old, or there about, was under extreme stress with all the comings and goings, and running around after my father with the constant round of doctors visits, buying all the dressings for his bed sores, liaising with all the agencies etc. She would get very upset when senior family nursing people, and social services people, would point out her inadequacies. Basically, they were annoyed at her for not being 20yrs younger!

Occasionally, social workers would give mum 'respite', perhaps once a year, and dad would go into a home. But they judged mum to be far too wealthy to be worthy of their funds because mum and dad owned their own house. They would not recognise mums careful housekeeping to pay for carers and make ends meet.

I would fight the agency battles for mum as best I could. Trying to get dad day care sessions and lifts etc.

When LTC was formed, it was a real step forward, or so it seemed.

The LTC team at social security were very good, and helped me understand the system in detail, which I think is a good system.

The evil section of people were the social workers, who drove my mother to have a stroke, and me to require treatment for depression.

Firstly they are a department in a constant state of crisis, (for both adults section and children section I believe) a simple request for data of staff turnover would confirm this.

When I understood the mechanics of LTC benefit, I was keen to enrol my father to ease mums financial pressures. Soc sec said dad would need to be assessed to confirm a level. I was told the social workers could do this. The social workers lied to me that ONLY they could do this, and I would have to wait 2 weeks.

I waited two weeks, contacted them again, and was told dad wasn't a priority, at that time I wasn't even allowed to speak to a social worker, they had employed a 'fire wall' secretary to 'fence' calls and protect the social workers from the public. When someone finally got back to me, I was told dad would have to be 'referred' to them by the hospital or a doctor. (Keep in mind that he was known to them, and had had 3 different ones in two years I think.)

By the time all this had happened, dad had another urine infection so into hospital he went. At that point, I was able to push for the referral for assessment.

The lie was that ONLY social workers could assess. I later found out that doctors and other health professionals can also assess for LTC. Had I know that a lot of pain would have been saved.

Well the ball was rolling, but too late, when dad returned home, the stress on us all took its toll, I popped over to my parents to check on them, took one look at my mum, and.. glassy left eye, drooped mouth, slurred speech, weak left arm!

I had warned the social workers and social services this would happen. And mum was rushed off to hospital with a stroke.

Dad went into a home on as an emergency, that was at the beginning of the April 2015. He was finally assessed for LTC as level 4. I had to explain to him that he would never live at home again, his needs were just too great for mum to live with, and she could no longer care for him as she had done, with the driving, doctors visits, carers in and out all the time etc.

Dad gave up really, and died at the end of the following June, just three months later.

So in summary.

LTC is great.

Access to LTC diabolical, shameful, cruel. Do I need to go on?

How on earth does a person without a very vocal advocate, ever get assessed? And if someone is assessed as a level 1, how do they ever re-access the system to progress as their needs get worse?

I know the system is open to fraud, but the incompetence of the social work team and social services just adds to peoples pain, and prevents money going to where it is needed, arguably because of the staff turnover of social workers, they never form a relationship to spot fraud! Or need!

The social worker department needs urgent sorting out, if it continues as it is Jersey will appear in the national news with its own 'baby P', Or elder citizens will die

through systematic neglect. The question will be asked, 'How long has Jersey authorities known, that its social services and social worker department in particular, was totally dysfunctional?'

A system of access to LTC is needed that welcomes people, helps people when they need it, lifts up and supports people. If the system can only be accessed by 'crisis referrals' as it was, and I hear still is! Then so many people are missing out and being driven to despair.

#### **Submission 4:**

I am in full time care as i need 24/7 care. We did all the right things took out insurance policies and bought a house so as not to be a burden to the states but now find that i am paying Very Dearly for this the system is 2 tiered the haves and the have not this is Totally unfair and should be reviewed .Everyone should pay for health care even only £10 per month .I pay tax plus extra old age care because of my condition if my temperature rise by 1.5degrees i have to call the doctor and my bills can be high. Because in my opinion the Hospital should pay the bill they use the word Care to avoid this -as for SS they have not sorted out my costings yet despite my Son asking them (my son is my power of attorney and acts for me as i cannot deal with it)The other morning on radio the SS President advised people to take insurance policies for later life i would say don't bother because as said before it has cost me dearly this needs to be reviewed urgently and more fairly than what it is at present.

#### **Submission 5:**

Jersey unfortunately is heading towards a total socialist society where large sections of the community are benefiting by those of us that have more than one job and pay huge amounts of tax into the social system. The amount of tax I pay is ridiculous compared to any benefit I get from the system I pay into.

It is totally unfair that I would still have to sell my house or take a loan out on it if i was injured or had need of long term care whilst there are huge sections of our society who are paying next to nothing into the system whilst taking large amounts of money out of it.

I would like at some point to be able to keep some of the money I earn to spend on what I want, not what the states of jersey wants. Spending and taxation is totally out of control with people paying nothing into the system whilst taking everything out.

Under no circumstances should the amount of time be lowered to allow more people access to the system who have not paid a sufficient amount into it thus putting more strain on those of us who are paying a large part of our wages in tax.

There should be NO increase in the amount of tax we are paying people are struggling to make ends meet and this will only add to a very stressful situation. The LTC is a failure and I will still have to sell my house I have worked all my life for. As well as subsidizing those who have had large amounts of income support given to them and new social housing.

Finally the states must cut spending and not increase taxes.

#### **Submission 7:**

I refer to the advert in the JEP regarding Long Term Care Scheme.

Last April 2016, my mother in law had to go into care. We applied for benefit, but after much chasing around for a reply, we were told she could not have assistance as we put her down as Life Long Enjoyment on our house. Effectively we are meant to be paying her rent, for a house she never owned. We also sold our last property to do up this one as it had no electricity and plumbing and was all funded by myself and husband. When we put her down for life long enjoyment it was in 2003 and just because a new law came into effect in 2014, we should not be penalised. We appealed and again after many letters, we were told our appeal had not been successful and we would have this in writing. Seven weeks later I got the letter and was told I could go to tribunal but only had 14 days to appeal and we were away for four days and with Christmas Day, Boxing Day, New Year's Day plus the bank holidays, this meant no hope of going forward.

At this present time, I am now doing extra hours to keep my mother in law in care as should she go home she would not be able to cope. She has been assessed as level 2 and we have letters from the Doctor and kidney specialist to say she is unfit to stay at home.

The improvement to the scheme should be to help these people who paid all their life into social security, worked hard to buy their own property and not be lazy. These lazy people are being cared for at our expense.

This is not fair on our family as my husband was hoping to retire in 5 years' time, but we now have to keep working to pay for funding.

#### **Submission 9:**

My Dad is a fee paying client of St Helier House and he has not paid (we think) his full amount of fees before we can claim an allowance. Meanwhile Dad has two pensions and a property he rents out (he has life interest in this) and money in a bank account which is rapidly being depleted.

The problem with this for me is that he is still taxed on the total of his income, i.e. his pensions and his bank interest and for long term care although he is currently paying this, I think this is wrong, I think those who are paying their fees should be able to claim this as a tax deduction by adding it to their tax form.

The second concern is more to do with mental health, my dad had suffered a big breakdown when my Mum died and he was in a ward at St Saviour's - he briefly went back home with aid but this was nowhere near sufficient and we quickly found him a place at St Helier house, his health has since perked up as he is not so anxious now - he remains under mental health care and on anti - depressant's/psychosis drugs but we have been told that he won't be eligible for much of a reduction because he doesn't need a lot of care, how does this work? If he wasn't there he couldn't function?

#### **Submission 10:**

I write concerning the long term care provision for the elderly. My mother entered Pinewood at the age of 96 and it was only when she fell and entered hospital that it was realised she had not been assigned to a social worker and had not been receiving money from the long term care provision, even though she had been in Pinewood for more than two years.

Similarly her sister who is now 96 has been in Pinewood for over two years and has paid over £50,000 but had not been referred to a social worker and hence was not on the register to receive the money from long term care.

When I raised the subject with the manager, I was told that the nursing homes were not allowed to be informed whether the person was receiving long term care or not.

My mother has recently been moved to the Little Sisters of the Poor and on the application form for entering the home it asks whether you have a social worker. It seems that a social worker is needed to assess each person who receives long term care. Would it not be easier for the residential home to be asked to inform Social Security after a person has been in their care for a year when they would have paid the £50,000. In my aunt's case, her sister of 90 was dealing with her finances and had no idea that such a scheme existed until fortunately I became aware that my aunt was not receiving any income except her pension and have proceeded to put her in contact with social services.

A way needs to be found that nobody slips through the net and fails to receive the long term benefit when it is due to them.

### **Submission 12**

I have been involved with the LTC system for just over 2 years and have had a few problems related to the system.

My Mother needed the LTC system (Level 3) from January 2014 due to her having Dementia and Alzheimer's. The system was slow and mistakes were made from the LTC system. Due to my parents' home being valued at £475,000 a loan was needed to cover the care cost cap of £53,060 once the cash assets of my parents were reduced. Due to my mother's problems Dad had to have Curatorship for mum which added further complications. Mother passed away in October 2016.

Dads health has deteriorated since mum passed away and after a fire in the kitchen and other health related problems, Dad was assessed and deemed to require LTC Level 1, care at home, which he has been having from Dec 27th 2016. I have POA for my father. Yes things may be complicated with me not living on the Island but surely in this day and age of emails and mobile phones this should not be a problem! I was in the Island from the 16th Dec 2016 as Dad had been rushed to hospital. I did not leave the island until the 6th Feb 2017.

Due to Dad having no cash assets left having used them for Mum's care, he requires to use the Loan bond to pay for his care through the LTC. I applied on the 27th December 2016 and was told it should take about 10 days to sort! After many contacts with the LTC team and them stating I was a priority we still do not have the paperwork to confirm all is okay with the application. I have just phoned the LTC team to find out how the application was going to be told it is at "higher management" level for signature and we are top of the list !

There have been many problems encountered by myself and my father with the LTC procedures including the LTC team making financial errors stating that my parents had more money than they had due to the LTC team putting information down twice for the same bank account and not realising that the property bond needed to be actioned now and not in 6 months' time.

There were also problems with setting up the curatorship and the accounts. The LTC financial side want accounts jointly and the curatorship separate which does not help with the confusion in setting all this up.

My final statement should be... Yes the LTC system is a wonderful idea but the system seems very difficult made by a lack of communication and a time scale that seems VERY long winded. Fortunately I am still around BUT if there were no family members around that were in there 50's, Dad at the age of 83 is also getting confused and forgetful would not be able to cope!

### **Submission 13:**

Regarding Long Term Care Scheme. 1. Experience of Assessment Process. 2. How long before receipt of benefit. 3. If could make improvements what would I do.

I am the daughter of a couple 91 and 97 who are now on the Long Term Care Scheme. I applied on the onset 4/08/2014 along with everyone else. It must have taken 10 months before anything happened due to the great demand.

Then a lovely social worker arrived to see my parents with a very comprehensive interview which followed with pages of report about both of them.

My mother (then in her 90th year) who has dementia was finally put on to the Scheme 18/09/2015 (nearly a year later) but this was back dated to the onset. My father even though 95 was considered too able and independent.

However things have changed with him and with another interview he was also added to the joint scheme from June 2016.

Having reached the cap in February 2017 the care at home by the company All Care is now mostly covered for the time being from the Long Term Care Scheme. This does not include the hours I do or the cleaning lady does. (Dressing my mother and making breakfast) My mother was again visited last week by another social worker. (I had not requested this) to check that all was well and if the Care Company were doing their job and my parents were being looked after properly and rules were being met regarding mostly medication giving. I think this has all been very efficient finally and couldn't have been better but that was because I was aware of the Scheme and knew what to do.

There are still a lot of people out there who are not aware or are not able to sort for themselves. Think the more vulnerable need the help.

### **Submission 15:**

My mum is 81 years old and has severe Alzheimer's disease – her deterioration is weekly.

She came to Jersey from Ireland in the 1960's and spent her life working at St Saviour's Hospital.

This is my experience to date of the care system to date

1. My mum is under the care of the memory clinic (excellent care)
2. In October her consultant advised me he was going to contact social services as he wanted to start the process of admitting her to a care home

3. In January at her next appointment her consultant advised me she now needed to go into a home – and asked where I was in the process – I had not been contacted by social services at this point
4. I subsequently received a call from a social worker and arranged a time to meet for which I needed to take the afternoon off from work
5. The social worker did not turn up or bother contacting me to explain what had happened
6. I called her the following week and she said it was 'ok' as she had arranged to see my mum herself I told her this was not acceptable as my mum was vulnerable and I wanted to be there when they met – despite this she tried to visit my mum but couldn't find the house (the only reason I know this is because there was a message on her answerphone)
7. We re-arranged another meeting – she spent less than 10 minutes with us – I asked her some questions about LTC – she could not answer any of them – provided me with a leaflet and said 'all the answers are in there'
8. I read the leaflet (from SSD) which is unintelligible – I asked my sister to look at it to see if she understood it (she is a teacher with a degree in English) not only did she not understand it she said it was the worst piece of English she had ever seen written – I am not sure if you have seen this leaflet, if not, it is worth reading to see if any reasonable person could understand how they access LTC and what their entitlement is
9. As I did not hear anything from the social worker I phoned her (twice) and asked what was happening she told me she was writing up the report.
10. I phoned her a third time at which point she told me she was leaving the Island that day but assured me she would finish the report and send it to SSD
11. Having heard nothing I emailed SSD and asked if they had the report and how long it would take them to assess my mum
12. I subsequently received a call from social services advising they needed to meet my mum to assess her – when I queried this (as it had been d/w some weeks ago) the social worker advised the report hadn't been written up – I asked why she couldn't write it up from the notes – she did not have them (or could not find them)
13. I arranged another meeting (and another ½ day off work) to meet the social worker (who was very professional) and went over all the same questions again. By this time my mum was in a wheelchair – I queried why someone from the OT dept had come to see my mum some 6 – 8 weeks earlier provided her with a walking frame – but had not thought to follow up this appointment to see how she was getting on or whether she needed additional support
14. The social worker arranged for someone from OT to come the following week – she provided a bed guard, and a commode and advised the wheelchair wasn't 'very good' I said that was because I had borrowed it from a friend at work as I hadn't known what to do when my mum literally could not walk anymore – she said she would call round and arrange to fit my mum for a wheelchair I haven't heard anything since.
15. The social worker arranged for a care provider to call round and they have provided a really nice care worker – but this costs – my mum has limited funds – and whilst it is all very well for the social worker to say get them in for more hours (say at the end of the day) she really cannot afford this.

This whole system feels fractured to me – there is no co-ordination between the GP/ Memory clinic/ social services or SSD – it feels like they just want to keep the 'client' at home for as long as possible (which I understand if that person is able to function with care and they have adequate family support) but this doesn't seem to be a concern. I work full time and have 3 young children to come home at the end of the

day to a demanding parent who can hardly walk then needs personal care and putting to bed – to me – is someone who should be in a care home – surely – I feel very much that because my mum lives next door to be the box has been ticked that she isn't vulnerable as I am on hand 24/7 so there is no rush to sort anything out. And I feel I have no time frame as to when the report will be written or when SSD will assess her – that adds to what is already a very stressful situation.

Alzheimer's is a horrible illness – it destroys the person but it also ends up (in part because of the poor care system) destroying the bonds and the family.

## **Submission 16**

My father-in-law has been diagnosed by his GP as suffering from Alzheimer's disease. I was appointed his Curator on 29th July, 2016.

My father-in law has two adult daughters both resident in the Island

On 4th October, 2016 we spoke with XXXX at Single Point of Referral ('SPOR') and requested that the process whereby father-in-law could be registered for the Long Term Care Scheme be set in motion.

XXXXX indicated that we could expect to hear from her in due course. As she had not contacted us we rang at regular intervals both before and after Christmas. XXXX was seldom available on these occasions, but we were always promised a return call which never happened.

By mid February of this year because I was becoming more than a little frustrated by the lack of action I started to make waves. By this time my father-in-law was in hospital having gone out, in his pyjamas, at sometime during the night to obtain help for the other occupant of his house who had had a fall. Father-in-law himself fell over outside and was found the following morning by a carer suffering from hypothermia.

I was contacted by a social worker at the hospital who recognising the past failure of SPOR attempted to move things forward. I also contacted XXXX at Social Security.

I further contacted the Alzheimer's Society locally who were a very useful source of advice as to how to work within the bureaucracy that is the Jersey Heath & Social Security System and the Long Term Care Scheme.

Finally I contacted the Safeguarding Partnership Board and explained in some detail why I was rocking the boat. This really got the show on the road.

The next day I received a call from a senior person within the bureaucracy who offered profuse apologies and told me that he would wish to meet with my wife and I when he concluded his investigations into why SPOR had done nothing, but in the meantime he would prioritise my father-in-law's application. He has yet to invite us to such a meeting.

Finally by a letter dated 23rd February, 2017 I received from Social Security Department, Centre for work, pensions and benefits the Long Term Care Scheme application form which I completed and returned by letter on 2nd March, 2017.

Having not received an acknowledgement of my letter by 23rd March, 2017 I rang XXXX and was told that various outstanding items, in relation to our application, were being collated and that I could expect to hear more 29th March, 2017.



Give or take that will be nearly six months after we first contacted SPOR, and still my-father-law has not, so far as I am aware, been assessed! He is now receiving 24 hour 7 days a week care at home.

How would I improve the scheme?

1. The staff who are administering the scheme appear to be lacking in simple administrative skills. They do not return telephone calls and neither do they acknowledge written communications. Keeping applicants in the loop with information is so important, particularly when they are elderly and worried.

2. The applications which are awaiting attention are, so I was told, kept in a filing cabinet. As such nobody could give me any idea where my father-in-law's application was in the waiting list, and when it might be dealt with. The system (or more correctly the absence of a decent system) appears to be running the staff, rather than the other way round. A little computerisation goes a long way.

3. The explanatory leaflet handed out in relation to the scheme leaves much to be desired. It is repetitive in some matters and lacking explanation in others. The leaflet needs redrafting so that it is understandable to the end user, which currently it is not.

4. It appears to be impossible to find out who is the senior person responsible to the scheme. This individual should be named and his/her contact details promulgated.

5. The overall impression I get is that the scheme was launched before it was adequately staffed, and before systems and management controls had been put in place. What is needed is a root and branch review of the whole way in which the Long Term Care Scheme is "organised". I would employ a firm of business consultants to do this so that there is the necessary element of independence. It is not lost on me that trying to tweak a broken system to make it work is very much more difficult than making sure that it is fit for purpose before it is launched.

### **Submission 18:**

We have experienced being involved with the LTC scheme for both of our Mothers. My Mother has Dementia and Alzheimer's which has made it impossible for my Father to care for her as his health is not the best and he is 89 years old this year. We had to move Mum into care whilst Dad was in hospital having a major operation and, luckily, we were able to find him a room in the same Care Home when he came out from hospital and was very weak.

It soon became obvious that this Care Home was the best place for both of them but the costs are very high and they had minimal savings. So we applied for LTC support.

From the time of applying to receiving support was 11 months! Admittedly the financial support was backdated but it was only through the financial support of the three children that our parents were able to stay in care. It took ages for my parents to be assessed and even longer for the process of approval/rejection. The whole scheme did not have enough staff and the process is long winded.

My Mother continues to be happy in the Care Home but we, the children, do not know what happens next! There is little support to advise whether Mother will be re-assessed as a matter of course, as her health deteriorates, or whether we have to

start all over again. Also, at what point will my Father be eligible for financial support? Will this be before the bank account is finally empty and the children are financially supporting them again?

The second instance of LTC in the family was with my Mother-in-law. She was ill for many years but, luckily for the Social Services, we had the foresight to build a "Granny Flat" onto our bungalow and we became her carers – with no financial support. It was only when she became too much for us to cope with her needs that we were able to place her into the same Care Home and request financial support from the LTC scheme. This time, 18 months later, the process took less time – even though there still seemed to be the under staffing issue – but I understood the system better and was able to chase the right people to keep things moving. The financial support arrived within a month of her passing on.

So, we both believe that it is a great scheme and is very necessary to support those in need in their final years and their carers – especially as we have a growing aging population. However, we believe that it is under staffed and bumbling along without the right investment into the running of the scheme and the people that have to support it.

### **Submission 19 – Little Sisters of the Poor Care Home**

I have been asked to respond to the letter recently received concerning Long Term Care Scheme Review.

1: Regarding waiting lists.

We do not normally keep a long waiting list as we admitted Residents according to their actual needs at a particular time. As our Home is large and spread over 3 floors we need to choose suitable Residents for any given vacancy.

We are finding it difficult to get a Social Worker involved, there is often a long wait between requesting an assessment and the involvement of a Social Worker. This has at times resulted in a discrepancy in date when fees were paid. I would have expected fees to be paid from the date of requesting assessment and not from the date the Social Worker visited.

2: Resources to deal with Assessment.

When a Resident applies for admission to our Home we make our own assessment of need. Our grading does not always correspond with Social Worker assessment. Recently one of our existing residents was assessed for Long Term Care, the Social Worker phoned to say that he did meet the criteria but a few days later I was informed that long Term Care would only fund him for a lesser amount than would normally be paid for level 1 residential care. I feel that Social Workers make assessment on a one off visit and do not appreciate that elderly residents function reasonably well within a secure environment but would be totally unable to function effectively on their own.

3: The transition to the Scheme.

We always advise families of prospective residents to contact Social Services even if they are self funding. There has been one minor problem when a Resident was self funding and had passed the single £52,120 but had not been informed by Social Security that they had reached the care cost cap. The family had a difficult time trying to reclaim the money overpaid for the Mothers care.

4: Eligibility Criteria.

I understand the present need for someone to be resident in Jersey for 10 years before they will be considered for Long Term Care. This can be a problem if an elderly person comes to the Island to be close to family and then need to move into residential care. Their income is often very low and yet they are unable to claim assistance from the state. Elderly people from Jersey who go over to the U.K. are entitled to claim assistance. I wonder if this needs to be looked at again.

5: The Approved Providers List and the care available.

We have not experienced any difficulties in this area. We are a Care Home with Nursing beds so we are able to provide care to our residents until death.

6: The process of the Scheme and how it is administered

There is still quite a long wait before benefits are paid for individual residents. The Home has not always received written confirmation of the breakdown of fees. Some residents/families request that funding from Long Term Care be paid directly to them and not to the home. We feel that it would be more simple for the home if all fees could be paid directly to the home. I know that this would entail residents pension being administered by Long Term Care. I don't know if this would be possible.

7: The Assessment Process:

As mentioned before our assessment of needs for individual residents do not always match that of the Social Worker. I am not sure of Social workers assessment criteria, but still feel that they make a judgement often after a one off visit. Residents can often give a false impression during an assessment process and it is only gradually that one realizes their level of dependency. Many elderly people hate to admit that they are dependent on others for daily activities. There may be a fine balance between maintaining independence and providing necessary assistance.

## **Submission 2.20**

To begin with, when the scheme was being rolled out, it was very confusing and difficult to understand. Perhaps that had something to do with my parents circumstances. I had to call upon the ltcs team for advice and clarification, they were a great help and I appreciated their support. They also found it confusing and hard to understand

Doing the financial calculations to assess if my parents would benefit from opting in or out of the scheme was a difficult thing to have to do, as it essentially meant having to estimate how long they may live.

The financial assistance provided by the scheme has been very welcome and does take a lot of pressure and worries away with regard to ongoing affordability of the nursing care needed by both my parents.

I did experience a possible issue with the scheme in relation to the assessment of care level. As you will know there are four levels of care support. My mother was assessed as level three, after some time we asked for her to be reassessed and she was moved up to a level four. However her specific situation had not changed and it was clear she should have been a level four not three. However as the onus is on the family to challenge we, we could not get backdated contributions at level four. As the specifics between three and four are quite fine, we had relied on and left it to the professionals who had assessed mum as we believed they would be experts in the matter. But it seems we should have challenged earlier. I know it does say any challenge has to be made within a short time frame but that is quite a responsibility to put on laymen in this area

My main concern is with what I see as the care homes seeming to see this as an opportunity to raise their fees and benefit from the schemes increased financial support available to their residents. This has implications for the ongoing affordability of care by residents and the future of the Itcs, as it seems obvious to me the 1% tax to raise funds for the scheme is not viable and will need to increase. This then impacts on many taxpayers and takes money out of the wider economy.

As an example I will forward to you separately two emails to my mother and fathers care homes sent recently in relation to their proposed fee increases which should be self explanatory.

To summarize I believe the scheme is a comfort to families who have parents that need nursing care and removes financial worries at a time of increased stress, and it is the right thing for Government to do, but there needs to be tighter controls in place by Government over the private sector providing the care homes, as without they are free to use the scheme to their benefit. A public/ private partnership would seem to be a better model.

### **Submission 2.21 – Dr Minihane**

I have 3 principal suggestions:

1. A simple algorithm detailing care levels and associated funding/respice - preliminary sample attached with associated e-mail requesting data. It may be necessary to have a 2nd sheet describing criteria determining level of need.
2. Free availability on paper/online of a simple pro forma allowing patients or their families to input relevant information prior to meeting with social workers. I would envisage something similar to forms used in insurance before meeting with brokers. This would hopefully streamline the current process which appears to be taking inordinately long.
3. A 'buffer fund' for those in hospital prior to their care/financial needs being established in relative perpetuity. This would allow more rapid appropriate discharge whilst arrangements are finalised. For those individuals who are subsequently found ineligible to be provided with States funding, by virtue of their assets, a repayment schedule/charge over their property could be put in place.

### **Submission 2.22 -**

I am an Agent for my Mother in Law, and found this whole process long winded, complicated and very very slow. The form is way to long and complicated and I work in Accounts.

We had two valuations done on the house, which social security ignored paying for a drive by which was a waste of time and tax payers money, how can you value a House by driving by!!!! it also came out £80,000 over our valuations, so we insisted on a proper Valuation to be, more expense and it still came back £25,000 over both of ours. All of this going backwards and forwards has taken over 4 months and probably wasted a lot of tax payers money. And to top it all she still has been refused any help until 2019.

Also there is talk of putting up Tax to help fund this, people working hard and paying there own way are not a drain of any funding yet we are the ones who are trying to

live on less and less each year, because it seems the only solution our politicians can come up with is "OH LETS JUST TAKE MORE TAX OFF THE WORKERS" and we are the ones who will never see a penny of this LTC.

I think the whole system needs to be re evaluated as it is not a fair system and as usual Middle Earners or People who have worked and have saved some money and purchased there own properties will loose out as usual.

Not impressed

## **Submission 2.26**

My comments with regard to the Long Term Care Scheme are from the point of view of a parish volunteer support worker, whose role has been to help elderly ladies with shopping etc.

Two of these ladies have in due course come to need residential care, and therefore access to the Long Term Care Scheme, and they have both been very distressed by the length of time the whole process takes.

The first lady was living independently at the age of 102, when she had a fall. She admitted herself to a Residential Home, planning to pay for herself for a couple of weeks then return home. Unfortunately she then suffered a stroke, which did not affect her mental faculties, but meant she could not return home. She immediately became very worried about the long term financial arrangements, fearing she would have to go to some sort of workhouse as her funds were limited. A referral was made to SPOR on 24<sup>th</sup> August 2015 and after three weeks a social worker visited, coming 9<sup>th</sup> September. On 3<sup>rd</sup> November the lady received a finance form to complete, which was done immediately. However it took until March 2016 before she was notified that the financial arrangements were sorted out.

I've been told that she could be considered lucky that it 'only' took 7 months for the finances to be arranged. This lady has no relatives and manages all her own affairs, and I assure you that it was extremely upsetting for her, as a person who has always paid her bills on time and never been in debt, to spend that length of time believing she was living there without paying her expenses. Although I frequently explained the system to her as best as I could, she naturally did not feel that my views were official and she wanted proper information and a solution.

My other lady is 94 and had a difficult year in 2016. She was admitted to hospital four times and referred to SPOR three times to my knowledge, but was never seen by a social worker. This March she suffered another fall and is now in Samares. She has decided she would like to go into Care and a referral was made to SPOR early in March. Thus far no social worker has visited and she is very distressed not knowing what the future will hold. Personally I cannot advise her on the possibilities and vacancies in the Residential Homes, or what the financial implications will be and she needs that information. Her 85 year old sister is willing to come from the UK and look after her, so she is even contemplating doing that, but I fear that would mean she is dropped from the waiting list yet again.

I'm not sure whether you consider that these matters are relevant to any discussion on the application of the Long Term Care Scheme, but they are maybe a knock-on effect of the amount of administration and paperwork that is needed to implement it.

From my experience, when a social worker does appear, they are very kind and considerate people, but the waiting list for referrals is most unacceptable.

### **Submission 2.27**

Whilst I applaud the chance to comment on my experience of the Long-Term Care Scheme, I regret to say that it has been an extremely frustrating one.

My mother went into a residential home prior to the start of the scheme. Accordingly she paid for her own care for a couple of years before applying. It took me the best part of six months to obtain an application form from Social Security and necessitated several 'phone calls and visits to receive the desired result.

I duly completed the application on my mother's behalf and after many months received the reply that she would be considered for receiving funds from June 2018 when she will be 101 years old! We were invited to appeal the decision within 21 days which we did and, no less than 10 months later, in November 2016, having used up most of her savings and necessitating me having to put my hand in my pensioners pocket to the tune of some GBP5,000, she received the benefit she was due and a year's refund of excess fees she had paid.

Just as everything seemed rosy and I had begun not to worry that she could not meet her outgoings, my mother was very ill in January. The result has been for the home to charge her high dependency fees because she needs more assistance on a daily basis.

I contacted Social Security and was told to 'phone the duty social worker. After three attempts I seemed to get through to somebody who understood her plight and that we need someone to come to the home to reassess her in order for her to receive additional funding to bridge the gap between what she can afford to pay and what she is being charged. Some eight weeks or so later, nobody has called to arrange a reassessment and I shall be obliged to keep banging my head against a brick wall until we get results.

What happens to the poor souls who have no children willing or able to fight for their rights on their behalf?

I would like to suggest that when a home decides for good reason that they must increase fees for a resident that they apply to the care scheme direct without the need for reassessment by a social worker. It is surely logical that a resident who is now 100 years old is only like to deteriorate rather than improve and will therefore need ongoing increased financial support. One can only assume that the need for a social worker's assessment is part of some audit requirement.

I could go on and on but hope that this message shows in some way the utter frustration with a potentially good scheme that is not being administered in a timely manner to the detriment of our old folk.

### **Submission 2.31 –**

My mother (90) fell on the 28th December 2016 and taken to hospital for surgery. We looked after my elderly Dad (91) until my Mum was sent home on the 9th January 2017.

On her first morning home she phoned for a ambulance to take her back to hospital, when the ambulance arrived they managed to persuade her to wait until her painkillers took a effect.

She had daily visits from home care and visits from district nurses, but still could not cope at home with several toilet accidents. My father although reasonably fit has a problem with short term memory loss.

We were due to go on holiday on the 16th January, it felt this would not be possible unless they both went into a care home at least until Mum health had improved.

After many phone calls to Social services and several emails from our Constable John Refault, they were taken in St. Ewolds the day after we left for our holiday.

My parents have no money apart from a little to cover funeral expenses, the house they live in was sold by my parents in 1999, to a private buyer, but have life time enjoyment of the property.

The money there received for the sale of the property has been spent by them to supplement their pensions and as not been given to myself or my brother. On the 27th February I had an appointment with Social Security Long Term care department and gave them the bill of sale for the house and all my parents bank details and the last three months bank statements. The only one I could not get from the bank was the last statement for their deposit account, which my daughter gave to them a few days later.

After many phone calls asking if and when Social Security will pay for St Ewolds and the full time career they now have, we cannot get any answers.

My parents have not received any accounts from St. Ewolds or the home care provider, so we have no idea who is paying or if they are waiting for Social Security to fund the care.

My parents returned home from St. Ewolds on the 10th March with a full time career from a company in England.

My contact with Social services has always been very helpful and has organized the care at St. Ewolds and the home care.

Our frustration is that Social Security Long Term care department has still not been clear if they will cover all the past and future expenses incurred by my parents and is very worrying for them and the family.

They have no money as such, so if they do have to pay all the costs what will happen to them.

### **Submission 2.32 – from Care Home**

#### **To examine existing resource and manpower provisions particularly in relation to:**

##### **a. The assessment process**

In the initial stages there were huge delays in the assessments getting completed and through to Social Security, this appeared to be due to challenges around Social Services manpower and the time it took for the required training. Equally the Social Security Department had delays in completing the process, again this appeared to be

due to staffing challenges, The lack of understanding of the scheme by the general public and specifically applicants must have further compounded the problems.

b. The current waiting lists

The scheme seems to be more effectively administered now by Social Security and the team is very responsive. If problems present they are very proactive in dealing with them and communications are timely. From some families have reported encountering problems that have taken a long time to get resolved. That may be because the system is very complicated and difficult to understand if you are not financially minded. An observation from claimants perspective is that there does seem to be long delays for families asking for re-assessment from Social Workers when a service-user's dependancy increases, one example was a request was made in January which has only just been completed. This certainly impacts on service-users getting the correct benefit in a timely way.

**To consider measures that might be taken to improve public understanding and confidence in the Long Term care Scheme.**

It should be noted that Social Security officers have taken some steps to improve this. A recent public meeting was held attended by 90 members of the general public and numerous Social Security Officers. As well as a presentation on the scheme individuals were given the opportunity to have their concerns and issues discussed on a one to one basis with a SSD representative. The general consensus from the attendees following the meeting was it was very helpful and certainly well received. More of these public events would be useful as the ageing population will result in more people applying for this benefit. More user friendly leaflets should be made available in Parish Halls and other public areas throughout the Island.

**Submission 2.39 –**

My 21 year son was receiving respite care through the states of jersey. Due to a complete breakdown between management and ourselves he has no longer been receiving any sort of respite care since December 2015.

We are now in the process of our son going to be receiving respite care through Autism Jersey shortly. Because Autism Jersey are a provider of service we have been told that his respite would have to go through the Long Term Care Scheme. We are resisting this due to the following:

Our son would lose his care component from his Income Support to the value of £145pw leaving him with the standard amount for an adult on Income Support which is £92.12.

With Autism Jersey taking over our son's respite we would still have to pay for all of his outings / meals out costs / petrol for car being supplied which would be impossible with the £145pw reduction.

At present the extra £145 pays towards all of our son's outings / meals out costs / petrol / replacing communication devices that he breaks often / replacing or repairing items in the house that he breaks / toiletry items that he still needs.

Due to our son needing constant supervision and at least a 2-1 ratio of support with Autism Jersey, his care package will exceed the amount payable from Social Security and would then have to go to the high cost panel at health every time he will need his hours increased as he ages.



We are finding it hard to understand why respite service is even included in the Long Term Care scheme. We as a family care for our son 24-7 and are only asking for 15 hours a week respite for our son. When he was in respite through the States of Jersey he was receiving 35 hours a week care which was going to be increased to 49 hours per week. To then be told that for our son to receive 15 hours pw he will then lose the £145pw from his Income Support is a slap in the face to us for caring for him.

We wouldn't mind as much our son losing the £145pw if Social/Health look into the fact that his care package should then include the extra costs involved (i.e.) outings / meals out / petrol for his transport / replacing and repairing items and communication devices so that we would not have to incur these costs ourselves. The benefit of doing this is that then our son would remain at home for longer which in turn would save the states. We are well aware of the cost to the states of our son going into full time care and also the size of a care team it would take to care for him.

Yes we do receive a carers allowance for our son which is a 4 weekly payment of £816, which you have to care for someone for a minimum of 35 hours a week to receive. This sum equates to a hourly rate of £5.83 over a 35 hour week which is well below the minimum wage. Also taking into effect that our family cares for our son well over 35 hours a week, social security are getting a very cheap service of care from ourselves considering they pay care providers £970pw for the highest care level, which our son would be under in the long term care scheme.

At present Health have agreed to fund the 15 hours pw until the new long term care scheme legislation changes in July but then they want our son's care package to go through LTC. We are still in the process of disputing it coming into effect in July for our son has his own lawyer and independent advocate who are involved now also as they will be acting for our son's best interests as they had previously when we disagreed with the states with his care. We will not agree to move our son's care to LTC until Social / Health look into the matter of the extra costs involved in looking after our son and giving him a full active life out in the community.

### **Submission 2.40 –**

I refer to the public call for evidence in relation to the Long-Term Care Scheme.

My mother, currently receives the benefit and has done since the scheme was launched.

At the time that the scheme was introduced, myself and my brother attended a number of meetings with Social Security to have the scheme fully explained to us and as it was a new scheme it took a few meetings to get the arrangements in place. All staff that we met with were extremely helpful and if they were not able to answer our questions immediately, they came back to us with the relevant information.

Our concerns are not so much about the assessment process but more so about what the future holds.

In my mother's case she is sadly confined to full term care at Lakeside care home having spent some time at St Saviour's hospital back in 2012. After nearly 2 years in and out of St Saviours Hospital we were advised by Dr A that our mother should move to Lakeside to the new unit that the states were taking.

We had been paying towards mums care whilst she was at St Saviours and obviously the fees increased when she moved to Lakeside. I believe that we had

been paying the monthly fees for approximately 18 months before the Long-Term Care Scheme was introduced. During the assessment it was evident that our mum had already contributed over £50,000 towards her care over the previous few years and that coupled with her small amount of remaining assets meant that she was eligible to receive the Long Term Care Award. At the time of the assessment, the amount of the award, together with her small pension meant that this covered the monthly fees from Lakeside and also allowed her a small amount of pocket money each month (approximately £40).

We felt relieved as it meant that mum's remaining assets could be kept (this only amounts to around £30,000). Before the scheme was introduced, we were getting very worried that mum would run out of money as her savings were being used to pay for her care up until this point.

All was fine for the first year however the care fees have increased annually. Whilst there has been a slight increase in the long term care award, there has been a shortfall for the last 18 months or so and again we are in the position where the small remaining capital is being depleted.

One of the main things that sticks in my mind from the first assessment meetings that we had, was the fact that my mother had already paid a significant amount from her savings for her care and that her remaining capital should now be preserved. This is not the case and again it will not be long until we are in the position where the remaining capital has been depleted to make up the shortfall. I have expressed my concerns in writing to Social Security about this situation but was told that there was nothing that could be done.

#### **Submission 2.41 –**

I thought you may find the experiences of my parents helpful for your review of this service.

My father endured a disability as a baby when his right knee cap was removed following infection. Unable to bend his leg due to it being fused, he limped to get around. Difficulties increased with age and notably from his early 70's when gradually small adaptations had to be made. Following illness, he started to receive formal care (with FNHC) in approx. 2011 before the LTC payments commenced. He'd already paid out in excess of the £54,000 threshold when he was re-assessed for LTC so he was presumably in the first cohort.

There were problems with his assessment that my sister could recall better than I, as she generally did their admin. medical visits etc. She and her partner undertook lengthy research into the LTC and finding a solution for my parents as by this time my mother's condition was also deteriorating. They noted several teething problems with social security and health giving different information in the early days of the service and officers not knowing answers. Frustratingly, my father's pride was knocked when he was being assessed. One of the questions was "can you walk?" "Of course I can" he said, and he got up via his electric raising chair, asked someone to fetch his pulpit, and with someone else supporting him, he proceeded to take 5 small steps with a cumbersome walking aid. They were his last steps but from what I understand his assessment included that he could walk.

Similarly, when my mother was being assessed. "Do you need help with X Y or Z?" she would reply "no" despite her already needing help with these tasks. I was present

at the assessment and it was difficult for me to say “but you do need help with X Y Z” without looking like I was trying to get her LTC level falsely raised.

My father died in June 2016 before my mother’s LTC assessment was fully processed. My mother had received a late diagnosis of Alzheimer’s sometime earlier. Despite my father paying £52,000 prior to receiving LTC, my mother is now told she must accrue the same threshold based on a single person. From her perspective this is a double blow as her pension has fallen sharply following my father’s death. It also seems to go against the information provided on page 12 in the LTC general leaflet March 2017 V05 I would appreciate clarity on why they are / were not considered to be a couple.

### **Submission 2.42a – Les Amis**

On behalf of Les Amis, I would like to thank you for the opportunity to provide a constructive viewpoint on how the Long-Term Care (LTC) scheme facilitates and supports vulnerable people who access out services.

Unfortunately we have found the process from initial engagement in 2013 to its implementation in January 2016, to be largely disorganised and lacking in clarity and support through the transition from the old to the new system of LTC.

To document every issues that we have had throughout this process would be somewhat lengthy, so in order to provide you with some examples, I have enclosed two sets of minutes from meetings with various Minister and key parties within the Department of Health and Les Amis. I have also included a copy of a letter to the Director of System Redesign and Delivery in which Les Amis expressed serious concerns on several issues just two months prior to the deadline for implementation of the LTC Scheme.

Hopefully, these will give some insight as to what we were led to believe prior to implementation and how it actually transpired throughout the process, the result of which was a wholly disappointing and frustrating experience,

Currently, we still have almost 70% of residents who have not yet had a full assessment and who subsequently do not have a personal care plan in place. During the last two years, we have had numerous and regularly scheduled meetings with the relevant departments to address this issue; the latest proposal for resolution being an uplift in social work time to complete the assessments and bring the above to fruition. However, the enclosed minutes give a clear indication that this should have been addressed long before now.

In essence, the LTC scheme appears to have been developed for the elderly population who fit neatly into the benefit system. It is evident however, that our service users were not considered enough throughout this process and the fact that they still appear not to is testament to the inadequacy of the overall planning of the LTC scheme.

I am encouraged however, that the Scrutiny Panel are inviting feedback of the delivery of the scheme and with this in mind, I would welcome an opportunity to present some of the key issues that we currently have and some of those which we have experienced since its introduction in 2013, as the enclosed gives only a very brief view of these.

If you would like to allow me this opportunity, please don't hesitate to contact me at your earliest convenience to arrange a mutually agreeable time. Thank you for allowing this opportunity for review and I look forward to hearing from you.

### **Submission 2.42b – Les Amis – Letter to Director System Redesign and Delivery**

Thank you for your letter dated October 16th 2015, only received yesterday (29th October 2015).

A key issue that has been discussed at numerous meetings is the number of care hours required per resident which as you are aware, has dropped significantly in certain cases, even for individuals who clearly need the support that they are currently receiving. Whilst it is not appropriate to drill down into the individual personal support packages ('PSP's') within this letter, I recall from the Ministerial meeting in July that these would all be confirmed by 7th August 2015 and prior to this it was going to be confirmed by the 1st June. We sit here today in November, still without the full information.

The 'reason' provided by the Director of Adult Services at the Ministerial meeting on 26th October 2015, that such lengthy delays were caused by IT problems, is inexcusable. In a corporate environment, no business would survive if its staff blamed the IT section for such delays. Efforts would be made to deliver on a project – such a lengthy postponement would simply not be acceptable.

In referring to the specifics of your letter, you acknowledge that little time is being allowed for adjustments to headcount. This is of course a fundamental issue that has far reaching implications. In the absence of clarity around the total number of care hours, we cannot suitably assess the staffing requirement for January 2016 onwards. Even if we now get clarity by mid/late November 2015, it may well be that we are faced with significant redundancies that will take time and money to achieve and impact the viability of Les Amis in 2016.

As a business we have taken major strides forward in streamlining our operation; making a number of redundancies, reducing outgoings and refraining from investing in certain areas. We have already provided a clear indication of our likely financial performance in 2016 and this itself needs to be put in context. We are an independent service provider who shouldn't have to disclose to third parties what our occupancy rate or indeed break-even position is. We have done so to date, to be as transparent as possible, but it is an unusual step to take.

The commitment now given to transitional funding is, I am afraid, unhelpful in the format in which it is given and we simply cannot spend more time in meetings, providing further information and then have to run with a potential contingent liability, relating to pay back of the transitional funds.

In summary, we are focused on delivering the 'vision' of Les Amis, we have delivered on all the issues we promised to deliver on (including making redundancies), but we have been fobbed off with excuses from you for not clarifying people's care hours. It is understood that there are wider issues at play in terms of the State's finances, but in dealing with our residents, it seems that a computer glitch has resulted in not knowing if a resident who currently receives x hours, will now receive y or z. Surely if the only excuse here is that the IT hasn't worked, the more cost effective option would be to accept that the hours previously agreed for individuals remain the same for 2016 and be funded accordingly, rather than pinning hopes on a computer

programme which doesn't seem to fit for purpose. Such an approach would have also been far more cost effective and saved the numerous meetings held – including two Ministerial meetings – where we have simply ended up with the same result – no clarity as to the care hours/PSP's.

Accordingly, the transitional funding commitment is simply unworkable and seems designed to take up more administrative time whilst PSP's are (hopefully) finally confirmed. Therefore, we will not take up the offer in its current format and simply have to take the risk that the level of funding is such that it meets the (reduced) ongoing operational overhead. However, if we find that there is a significant reduction in care hours and thus funding, which in turn means that for a period we are over-staffed in early 2016, and this results in a further loss making position/eradication of reserves, the Board will have to carefully consider its position, one outcome of which would be to close Les Amis.

### **Submission 2.43**

I wanted to let the panel know of the difficulties I have faced concerning my father's application for the Universal LTC benefit.

He has Alzheimer's disease & a social worker started assessing him last April (2016). At the time my mother was suffering from cancer & at the end of May had to go to the hospice for pain management. As my father could not be left at home alone, the social worker arranged for a care agency to provide daytime care, which was extended to 24 hours care the day after the agency began. A week (beginning of June 2016) later the social worker said she would complete the Beka form for social security so the care we were paying for could start to accumulate towards the care costs cap. She advised to keep all the care agency invoices as they may be able to backdate the start date to when the paid care began. (My mother had previously been providing unpaid care for my father for well over a year).

The social worker said in July that she would get Social Security to send the forms to me, as my mother was back in hospice at this point. Following my mother passing away in August 2016, I came across paperwork from Social Security regarding my father's application for the LTC benefit that had been sent to her not me. I contacted Social Security to explain I had only just received the forms & was told at this point that the likely start date for my father's care costs cap would be 15/06/2016 (3 weeks after we began paying the care agency).

I completed the application form as my father's Agent for Social Security purposes. (I was subsequently appointed his Curator on 11/11/2016). As my father's assets were over £25k & he owned a house over £400k, he would only require the LTC universal benefit. Along with the form I enclosed a letter explaining when the paid care began together with the invoices.

By this point, my father had spent approx 2 weeks on Beech Ward & had then moved to Beaumont Villa (the dementia care unit at L'Hermitage care home). He also spent 2 weeks in the general hospital.

Eventually in December 2016, I received a letter from the LTC care team at Social Security stating my father's benefit would not start until approx August 2017 & the start date for the care costs cap was noted as being 15/07/2016 and 15/06/2016 in the same letter. I appealed this as I believed the 53 weeks (my father's care needs is level 4) would have taken him to around the end of June 2017.

I received a reply saying the time on Beech Ward did not count towards the care costs cap. Despite requesting that a second officer reviewed my appeal, the same officer responded. They also stated the correct start date was 15/07/2016 but could not explain why I had previously been told 15/06/2016 or why both dates were mentioned in her letter.

As Social Security, at this point, were unaware that my father had spent time in hospital in Sept/Oct 2016, I duly notified them of this hospitalisation & the date he returned to Beaumont Villa (10/10/2016). I also asked where the start date of 15/07/2016 had come from & was told that it was the date of assessment by the Social Worker & they had to take that date & any paid care before that date would not count towards the care cap costs. Due to the difference in dates 15/06/2016 & 15/07/2016, I asked to see the assessment paperwork & was told I had to contact the social worker.

I then received another assessment giving a date in September 2017 as being when my father would receive his universal benefit. The paperwork had an incorrect date of admission to Beaumont Villa as late October 2016. I immediately emailed the same officer at Social Security providing a break down of the dates my father was cared for by the care agency, Beech Ward, Beaumont Villa, Jersey General Hospital & Beaumont Villa to date. A month later, I still had not received a response. Due to a holiday & the requirement to complete an inventory for the court as part of the curatorship, I had not had time to contact the social workers office (my father's original social worker left the island in August 2016). I emailed Social Security about the lack of reply & was told they were waiting to hear from the health department.

I eventually managed to contact my father's latest social worker & she has ascertained that the Beka assessment form was dated 15/06/2016 a month earlier than Social Security maintained. She has notified them accordingly so I am now awaiting a response from Social Security as to when my father's LTC benefit is due to start. Hopefully after 8 months, they will finally provide the correct start date for the benefit, which I anticipate to be towards the end of July 2017 taking into account the time my father received free care from the States of Jersey Health department.

I have found the whole process extremely frustrating & somewhat confusing. I dread to think how many people have merely accepted the start date detailed by Social Security without question (I'm not saying all the dates are incorrect). My mother, during her illness, would probably not have queried anything & I suspect an elderly person dealing with these applications on behalf of a spouse may find the whole process overwhelming.

I am used to dealing with evidence based paperwork and, therefore, do not accept things at face value. In addition, if somebody appeals against a decision, a separate individual should then look at the case - not the same person!

Finally, I feel that is unfair that the paid care that was required for my father, at the social workers recommendation, due to extenuating circumstances with regards to my mother's ill health, cannot count towards the care costs cap, as it pre-dated the Beka form by 3 weeks. Surely, the care costs start date should be from the date the care was deemed necessary rather than the date a form was completed?

I would be happy to supply any relevant paperwork or correspondence regarding the above, if required. Similarly, I would be more than willing to discuss my experiences of the LTC scheme further if necessary.

## **2.45 –**

On a personal basis only, my daughter first joined the scheme in 2015 on moving into a community home. As much as we were grateful for the opportunity that the scheme gave her, my lasting concern was around the personal allowance, which at the time was approximately £32.00 per week. Without a supportive family she would not have been able to afford such things as clothing, hairdressers, social and leisure pursuits or holidays. For young people with a lifelong disability who are either unable to work, or who cannot find suitable employment, this allowance is not practical. They deserve to lead a fulfilled and meaningful life...not just survive!

When looking at the assessment of need, I would say that it did its job! However, I felt that it was very restrictive. Due to the nature of the form there can only be a 'black or white' response...life is not always like that! There can be shades of grey, but there is no scope for extra information. I believe it is down to the skill of the professional completing the form as to the outcome for the service user. It should also be noted that a lack of social workers can hold up the whole process. At this point it could be questioned as to whether a social worker is actually needed or whether an assistant could be doing some of the administrative work.

As a family, we found communication to be dire. We received confused and misleading emails, no written confirmation of the financial package and had to put up with an arrogant attitude from staff; this may possibly be down to pressure of work. However, some training on how to speak politely to service users would not go amiss.

Finally, on a positive note, my daughter moved back home at the end of September 2015. Her LTC account was closed, temporarily, as she was reassessed for domiciliary care, during this time she returned to Income Support and Impairment. The payments were all made on time with only a minor overpayment of Income Support. The Income Support Department was fully up to speed with all communications and very helpful.

## **2.46 – SNAP (Special Needs Advisory Panel)**

### Introduction

Over the past 4 years SNAP has developed a sound working relationship with Social Security via the Service User Forum; this partnership working has not only benefited service users by enabling them to put their opinions/suggestions to the department, it has also helped the department to appreciate, and hopefully understand, why and where issues lie.

Over this time it has been very apparent that some issues are 'easy wins' whilst some are much more difficult, needing a shift in attitudes and/or legislative changes. Regardless of this, SNAP greatly appreciates the effort that the Department has put into these meetings.

### Long Term Care Scheme

Alongside other pieces of work, SNAP has been looking at the LTC Scheme. The basic concept of this scheme is good, however whether it is achieving its objectives and how sustainable it is in the present financial climate is up for debate! Jersey has an ever aging population with the associated health issues. In addition, with the

improvement in health care, people are surviving longer with complex needs. It must be remembered that alongside this comes a need for: specialised equipment, adaptations to properties and well trained staff; not forgetting support and recognition for family carers to enable them to continue caring for their loved ones. **Without these carers the States would be facing a far greater bill to support these vulnerable islanders.**

When SNAP first started looking at issues relating to the move from the Care Component of Impairment, within Income Support, to the LTC Scheme, we saw far more cases where people were either incorrectly assessed or had unwittingly received both benefits. These mistakes led to huge reclaim bills being sent out to already struggling families. Our understanding is that though this may not have been completely resolved, it is much better than it was. Better communication between Social Security's departments, and an understanding that the service users need to know more about the interaction between both these benefits have helped to improve this situation..... having said this there is still scope for improvement!

With particular reference to the delivery and standards of care....SNAP was lucky enough to be involved in the recruitment process for both the Chair and Commissioners for the new Care Commission. SNAP was also involved in the consultation process around the Regulations of Care (Jersey) Law 2014. With that in mind, it will be the Care Commission's job to oversee these laws, once they come in to place later this year. It will be important for Social Security to liaise with the Commission and the Inspections and Regulations Department to make sure that care homes, care at home and adult day care services meet these specific requirements. Only those meeting these standards should be receiving payment via the LTC Scheme. Open and transparent partnership working between departments, and including H&SS, is paramount to the delivery of well planned, safe and user appropriate care. It is vital that service users are involved and made aware of the Care Commission, the Care Laws and the Inspections and Regulations Department. Service users should understand the roles of these bodies and how they relate to their everyday lives.....service users need be empowered to speak out when their care is not delivered in a safe and/or appropriate manner.

### SNAP's Outstanding Areas of Concern

#### OT Equipment, Disposable Items and Loss of the Care Component

Snap feels that this is an extremely important issue, having been contacted by a number of concerned families.

If families/ home care services are to care for individuals in their own homes they **MUST** have a safe and accessible environment in which to carry out this care. The correct equipment is an essential part of the safe delivery of care for both the individual and the care giver. Individuals may require transfer and personal care equipment, ramps/house adaptations and accessible vehicles. For those who have a sensory disability, though their disability may not be visible, it is just as essential for them to have pieces of equipment to enable them to function in daily life, both in the care environment and when accessing the wider community.

SNAP understands that the Occupational Therapy Services is subject to an equipment review. The Social Security Department is working closely with H&SS around the complexities of equipment including the problem of liability insurance.

Families have highlighted the costs they face when purchasing disposable items such as incontinence products, feeding tubes and buttons; these costs can really



mount up and put extra pressure on our families, who tend to be on a low income. The loss of the Care Component on moving to LTC is causing even more hardship, with the cost of these items reported to be as much as £500.00 per month. SNAP understands that disposable products are not **yet** included in LTC Scheme funding. From our work with Social Security, we also believe that the department is aware that there needs to be a better understanding of these products.

Historically the Care Component, which at a level 3 is around £145.00 per week or at a level 2 around £102.00 per week, was paid into the individual's bank account. The funds from the Care Component could then be used to purchase items related to care that were not provided by H&SS.

The LTC fund should either cover the cost of medical supplies and equipment required for the safe and appropriate delivery of care. Or individuals should continue to receive the Care Component, thus enabling them to purchase disposable products, and to save for any items **not** deemed as essential. To alleviate any concerns as to how this money is spent families could be required to produce invoices on request.

**All items deemed as essential should be funded through LTC.**

It should also be noted that there may possibly be the chance for disposable products to be purchased through 'Special Payments'.

Young People with Complex Needs: Transition

A well planned transition, delivered in a timely manner, will give all involved room to make sure everything is in place for the safe and appropriate delivery of care, including the necessary budgets to support their needs.

The lack of good transition planning has been a stumbling block for all involved: families, individuals, service providers and States' Departments.

It has caused massive problems for the States Departments, who seem to have been unprepared for these young people transitioning through the system. This lack of forward planning has led to needless heartache, uncertainty and worry for the families and individuals involved.

For the Long Term Care Scheme to work it is vital for all the departments to work together. Social Security must have a good idea of the numbers of young people transitioning through to LTC, including their specific needs and a timeframe to their transition.

On a positive note, SNAP understands there is now a Social Worker in place tasked to deal specifically with transitions.

Also, earlier this year, a weeklong transition workshop was held, including representatives from a cross section of States departments and other interested bodies, including SNAP.

SNAP is hopeful that this workshop will enable the departments to put into practice a transition pathway for all, which in turn will help to iron out these problems to the benefit of professionals and service users alike.

Terminology

It has been noted during our meetings with Social Security that there is an issue with terminology.

Social Security has acknowledged this is a problem and is working with H&SS to put this right.

As an example of this SNAP has been told that H&SS has various classifications for the term respite. Social Security need to be aware and fully understanding what Respite means. Therefore it is vital that the departments work together to produce a list of terms and their meanings; this would benefit service users as well as professionals.

### Personalised Budgets/SDS (Self Directed Support)

SNAP appreciates the work that has been put into the LTC Scheme. However, it does not provide a person centred approach, with too many restrictions put on how the benefit can be used.

Developing Personalised Budgets/SDS would enable individuals to have control over their own their lives, moving us towards truly person centred care.

SNAP is aware that legislation would need to be put in place to protect both the individual and to prevent any misappropriation of States money. However, in the long term there should be a reduction in administrative costs which would balance out any initial expenditure.

Taken from Disability Rights UK:

#### **'What is a Personal Budget?**

A Personal Budget is an agreed amount of money that is allocated to you personally by your local council (and other funding streams) following an assessment of your care and support needs. This is support that you decide and control, in other words you control the money for your care and support - Personal Budget. A personal budget is a statement of the amount of money needed to meet your eligible social care needs. It allows you (or your representative) to control the financial resources for your support and the way the support is provided to you. In Scotland, it is referred to as Self-Directed Support and offers the individual the freedom and right to self-direct your support.

A Personal budget is the route to achieving independent living based on the social model of disability. It assists disabled people to live an active life and participate in society. It enables you to achieve your outcomes stated in your personalising care and support planning.'

Refer to;

<https://www.disabilityrightsuk.org/personal-budgetsthe-right-social-care-support>

As we know Jersey is lagging behind in Disability Rights. However, with the recent Health and Life Opportunities Survey and work being put into a Disability Strategy based on these findings Jersey is heading in the right direction.

Personalised Budgets are an obvious choice to sit within this piece of work.

Finally, even though SNAP believes that this scheme was started with the best of intentions. SNAP believes it was started without a full understanding of the likely take up or an understanding of the complexity of the needs of the service users it was to support.

The department needs to work on in-house problems, so that people using the department get clear and consistent information. The service users need to feel that they are being put at the centre of the decisions around this scheme and that their needs are being listened to in a respectful manner and understood. Positive feedback and the power of 'word of mouth' will go a long way, in a small community, to boost public confidence.

Moving forwards, if the public is to have both a better understanding of the scheme and more confidence in its outcomes, there will need to be more openness between the department and the community. User friendly information that is readily available and open discussions on the subject via the local media or at an accessible venue might also be helpful.

SNAP would like to thank the Scrutiny Panel for giving us the opportunity to be involved in this review. And we look forward to hearing its outcome and recommendations.

## 2.49

- Here's a condensed summary of my experience with the LTCT.
- I am most happy to meet and be interviewed or try and flesh out points mentioned herein if it will help others as the whole process has been challenging from the outset. I am very happy to go into more detail but here are the salient points:
  - Interestingly a report on radio Jersey today (13/5/17) suggested that those people with Alzheimer related illnesses require greater funds than they can save the lifetime. They quoted a figure of £100,000 as the cost of care for someone with dementia in their subsequent lifetime. To date we have spent close to £750,000 on their care over the last 6 years so respectfully I think this estimate is woefully small for Jersey. At the time of our application a States chamber statement by deputy Pinel said applications were being dealt with within a month at most (around Jan 2016).
  - If you are self funding then the home can charge you more – i.e. considered to have > 25k savings even if in full receipt of LTCS - can be a difference of £900 / week per individual!
  - The LTCS initial process was fast.
  - When my parents ran out of funds the review process took 7 months! We were told that the application would be reviewed and

that we would have a decision within a month. At the end of this month we had received nothing formally so I contacted LTCT and again at which point he disclosed that because there was a gift involved in my parents state to myself this may have to be repaid. This was somewhat of a shock as this amount is significant and related to a gift that was made prior to the inception and knowledge of the long-term care scheme. The implications of this were immense to say the least. As this gift had been given by my mother in good faith from her portion of the cell of her property this was a surprise. This actually meant selling our home ( Recently purchased unaware of this potential new clause in the long-term care scheme) the implications for this were significant as being forced to sell our home to repay the funds would actually cost us more than the property was worth due to the high cost penalties that would be applied on both personal and business loans. It also meant that it would effectively bankrupt us and our business. We run a small local business and employ 10 people.

- We took legal advice at that time as a gift given prior to the inception of the long-term care scheme was the basis for the full night financial decision been suggested by the long-term care team. Before the long-term care scheme was enacted, we were unable to find a similar law in Jersey that would enforce this 10 year claw back. What is particularly interesting about this clause within the long-term care scheme and whilst I understand the reasons behind it, is that the gift was made in good faith by my mom without knowledge of the up and coming long-term care scheme law. Further my mom could have chosen to take this money and given it to Charity or gambled it all away and that would have meant that both my parents would now be receiving full financial support from the states of Jersey without being penalised. It seems ironic that someone who has saved all the lives and worked hard to create a home and saved for their later life is penalised for choosing to give some of this away to another family member when the same application of the law is not applied to other circumstances.
- We considered appealing against the decision and decided against it. There was a general consensus that it was unlikely to make any difference. We also considered mounting a legal challenge to the states Jersey but were advised that the legal costs could run into the £100,000 as there was no legal precedent behind our challenge (it being a new law and we may still get a resolution.
- In most cases of law that I can find there is an exception/allowance of the decision is made prior to the inception of the new law that and not then included in decision making to penalised recipients. Obviously a decision has been made in the states not to apply this principle.
- There appears to be little joined at thinking within the long-term care team I have just discovered my parents could have their doctor's bills paid for and that it is a decision of the long-term care team to decide this for this I have to resubmit thank statements. Why? It makes no sense. It should be an automatic entitlement.

- Little or no communication
- Unnecessary stress worry and anxiety
- We are local people with 2 children under the age of 6 trying to run a small business and care for my parents - Appreciate the need to draw a line in the sand somewhere – Appears to be no consistency?
- Nowhere to go to get proper advice and no one outside of the long-term care team seems to understand the challenges of the new law.
- There is very little information either on the states website or anywhere else about the long-term care scheme
- The statistics and amputations provided by long-term care team was confusing and difficult to understand and there is the expectation that it is up to us to pull apart to the calculations without underlying formulae to fully understand the determination. we were offered a meeting to go over the figures which we ultimately declined.
- It is difficult to speak to/communicate with the long-term care team and get a response or relevant guidance
- We have to accept that the long-term care team are there not to help they are there to assess applications.
- Very little supporting guidance from the states of Jersey
- Still very unsure of our position financially.