

# Jersey Alzheimer's Association

## Dementia Matters



### SUBMISSION TO THE HEALTH, SOCIAL SECURITY AND HOUSING SCRUTINY PANEL

#### HEALTH WHITE PAPER REVIEW: CARING FOR EACH OTHER, CARING FOR OURSELVES

Jersey Alzheimer's Association is a local charity whose main aim is to help and support people with dementia and their carers and families in the Island. Our current and proposed services and activities are listed on the attached document. Over 100 people use our services regularly each month and our website, [www.jerseyalzheimers.com](http://www.jerseyalzheimers.com) receives around 75 unique visits a month.

We have been very encouraged by the recent action taken by Health and Social Services to address the current problems with the Health Service and the work that has been done to try and identify the correct way forward. However, we are uncertain that these plans will actually ever come to fruition.

We are concerned for a number of reasons:

- The extra monies which will be required to implement the White Paper will not be available.
- Health and Social Services have started a number of initiatives over the years, which we have had involvement with, that have petered out without any action having been taken; specifically:
  - New Directions – we attended a number of consultations and workshops on the proposals but the report was never published.
  - Carers' Strategy – we were represented on the Carers' Partnership Group which was set up to ensure that the Carers' Strategy was being implemented in a timely manner. The last meeting of the Partnership Group was in 2010.
  - National Dementia Strategy – Health signed up to this strategy in 2009, after an initial meeting about how this could be implemented, nothing has happened.

We were invited to meet KPMG to give our views prior to the Green Paper being published. We have subsequently met Rachel Williams, Director of System Redesign and Delivery for Health and Social Services, and attended a meeting for Third sector representatives, both prior to the White Paper being published. Rachel also came to speak to our Friendship Group, a carers' support group, to discuss the White Paper.

Last October/November we were also involved in workshops to put together an Outline Business Case for a new Dementia Pathway. We were concerned that the vast majority of people attending were Civil Servants, managers and professional care staff, mostly from Health and Social Services, with very little representation from charities and only one carer attended, who is one of our members. This raised the concern that plans are being made for services that Civil Servants 'think' carers want and need and that may not actually be the case. At a subsequent meeting where we raised this concern we were told that it would have been 'too much' for carers to be involved which we found to be very patronising.

We also felt that some Civil Servants had their own ideas of what they felt should be in the OBC and pushed for this without listening to the views of others. We have subsequently heard that this was the case at another OBC workshop. There was also a concern that they were planning such huge increases in staff and services that would be too costly and that the whole OBC would be rejected. To date we have not yet had sight of the final OBC.

It has been made clear throughout that H&SS will be expecting more services to be provided by the Third Sector. They state that this is because they believe that charities and non-profit organisations can provide a better service for a lower cost than they can. The more cynical might think that this is the 'easy' option for H&SS. Our concern is that only a small number of larger charities in the Island have the infrastructure to be able to take on new services. The smaller charities do not have the manpower or expertise and would need guidance if they wanted to take this on. We worry that by expecting so much of charities it would cause people, who currently do a huge amount of voluntary work, to step away because they feel it would be too much for them to effectively run a small business with all the paperwork and reporting that would be required.

We are a small charity consisting of 10 Trustees, who all are volunteers and mostly retired, 1 part time manager (20 hours pw), 1 part time administrator (15 hours pw) and Saturday staff who run the Saturday Club. We certainly don't have the infrastructure or manpower to be able to expand significantly in a short space of time.

If charities do decide to take on the services there is a worry that they could be left in a vulnerable situation if Health delays payments. This has happened this year to a number of charities. In our case, and without informing us, instead of receiving our grant in January/February as usual, they decided to pay the grant in two tranches. We received half at the end of June and we have just received the second half, with no uplift for inflation which we normally receive. We have emailed all senior executives about this but have received no response. It has not impacted greatly on us because we rely on fundraising to cover the bulk of the cost of running the charity as our grant is only £14,160pa

H&SS have indicated that they want Jersey Alzheimer's Association to take on a number of proposed services as follows:

- Active Ageing and Wellbeing Centre. It has been suggested that the JAA might consider putting in a tender to run this, which is intended to be a 'one-stop-shop' for access to all elderly services.

- a) Why can this not be done by Health Promotion? They exist, but we are uncertain of what role they play in the community.
- b) Our charity helps and supports people with dementia and their families; we might not wish to become involved in Elderly Services in general as we feel this might dilute our ability to do the job we are currently doing well.
- c) We seem to remember that a one-stop-shop was set up some years ago by the States, but was not successful (?)

We agree that one of the problems in the past has been that people, who are often vulnerable, are passed from pillar to post by H&SS and various States' Departments at a time when they need stability and assistance in their lives but find the idea of the Active Ageing and Wellbeing Centre difficult to understand.

- Awareness Raising

We feel that we offer an excellent service with regard to awareness-raising and distributing information on all aspects of dementia. (See attached notes of our services.) We are continually working to improve this service, so is it necessary for H&SS to expend financial resources on re-inventing the wheel?

- Home Support

It is our strong belief that people with dementia should be enabled to stay in their own homes for their life-time or as long as is possible. Currently it seems that vulnerable people are being guided quite strongly into full-time care, whether or not it is their choice, and so we applaud this change in attitude.

There is no reason why people with dementia should not remain safely at home, provided the right Home Care Support Package is put in place to support them. This should be a H&SS priority as the initial financial outlay will be more than compensated for in the long-term, particularly when Social Security's Long Term Care Law is up and running. The JAA would then be able to complement H&SS Home Support services as much as possible but do not currently feel we are in a position to take on a full-time service.

Our one worry with home support is that there is no legislation in place for the regulation of Care Agencies. We understand that this is to be incorporated in the new Regulation of Care Law which has been on the cards for many years but is still nowhere near completion.

In the White Paper there has been no specific mention of respite care for people with dementia. We believe that if carers were provided with regular respite care, their ability to care for the person with dementia at home would be prolonged by some

time. At the present time we do not even know if there are any respite beds available and so are unable to advise our members.

Jersey Alzheimer's Association  
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