



Alzheimer Scotland  
Action on Dementia



# What do you think about short breaks & respite?

September - October 2006

A short survey of views from carers and professionals on their experience of current respite and thoughts about alternative options.

*If it were a whole day I feel I could do something worthwhile and not be rushed. I hope that doesn't sound selfish. (Renfrewshire Carer)*

*For there to be homes especially for respite; staff to be trained on dementia and everyone to get a fair share of respite. (East Renfrewshire Carer)*

*People have brought or taken their loved ones home because of environment. (West Dunbartonshire Prof)*

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## **Summary of Survey**

### ***What do you think about short breaks and Respite?***

#### **1. Background**

This survey was undertaken as preparation for a Shared Care Scotland workshop (October 26<sup>th</sup>), to ensure that a wider selection of views and comments could be presented by those present. The survey was circulated during September 2006 and collated October 2006.

#### **2. Area covered**

Argyll & Bute, East Renfrewshire, Inverclyde, Renfrewshire, West Dunbartonshire

#### **3. Distribution:**

- Having our Say Dementia Network
- Public Participation Forum and Dementia Interest Group members - West Dunbartonshire and Voluntary Health & Social Care Network - Renfrewshire
- Carers Centres
- Known dementia service providers in East Renfrewshire, Renfrewshire and West Dumbartonshire
- Alzheimer Scotland service users in Renfrewshire and Inverclyde
- There were two focus group discussions with 10 carers in Renfrewshire (Jenny Douglas, Involvement Officer) and 15 Carers in West Dunbartonshire (Margaret Oliver, Carer Support Worker).

#### **4. Response**

There were 29 individual responses and the 2 group discussions with carers. The collation has been a simple one, preserving in the main the individual comments given. Collection of views was the main intention rather than analytical comment. The sample is also a small one with a variety of views so use of percentages, averages etc serves little purpose. Interest in the responses has also been expressed by those responsible for developing respite/short break services in Renfrewshire and West Dumbarton. A simple presentation provides greater depth of information for a wider audience.

Where practical, responses have been split by geographical area. The survey format has been used as a collation structure with the 2 focus group responses highlighted separately throughout. Some of the Renfrewshire carers in the group discussion also completed an individual form at a later date as the group discussion only had time to focus on parts of the whole form.

## BACKGROUND AND SUMMARY POINTS

### 1. TABLE OF RESPONSES

| AREA                  | CARERS                             | PROFESSIONALS   | AREA TOTAL      |
|-----------------------|------------------------------------|---|-----------------|
| Argyll & Bute         | 1                                  | 1 (dementia resource)                                 | 2               |
| East Renfrewshire     | 2                                  |   | 2               |
| Inverclyde            | 1                                  |   | 1               |
| Renfrewshire          | 14 plus<br>10 in group             | 2 (Day care organiser, Social worker,                 | 16 (plus group) |
| West Dunbartonshire   | 1 plus<br>15 in group              | 4 (2 Social Workers, Carer support worker, CMHT (CPN) | 5 (plus group)  |
| Not recorded          | 2                                  | 1   | 3               |
| <b>OVERALL TOTALS</b> | <b>46 (21 +25<br/>from groups)</b> | <b>8</b>  | <b>29</b>       |

NB. It was not possible to deduce areas for not recorded responses.

### 2. PRESENTATION OF RESPONSES

Responses follow the format of the survey and are recorded in three parts:

*Part 1 Summary Points* Page 4

*Part 2 General Thoughts (Responses to open questions)* Page 5 - 11

*Part 3 Overnight short breaks (Responses to selection of models)* Page 12 - 16

*Part 4 Day/Evening examples (Responses to selection of models)* Page 17 - 20

## PART 1 - SUMMARY POINTS

Several key points are raised from responses that should be considered in addition to specific points. They are:

1. Strong preference for dementia specialist services rather than generic. Especially for small respite/short break unit.
2. Very keen on overnight breaks to be available via carers in person with dementia's home. (Very little available).
3. Frequent emphasis on staff to be dementia trained (i.e. have knowledge and understanding of condition and effects).
4. Lack of nursing home respite for people further on in condition.
5. Hard to plan overnight breaks in advance.
6. Current provision not offering much to younger people with dementia, particularly overnight breaks.
7. Carers sometimes want options for a break together as well as time to self.
8. Stage of condition influences preference of options. People wanted different things at different stages.
9. Those using day services and home support spoke highly of value.
10. Also keen on models not available to them presently - having funding and support to find/fund place of choice, dementia friendly hotels/accommodation, and places with care on site that have holiday feel rather than care home feel.
11. Discussion around respite in care home setting raised comment - *not at that point yet*. Where care home only overnight option many carers delaying use because they did not like option or felt person would not like it. Respite ceased to be preventative/carer sustaining. Would take break earlier if other options available.

## PART 2 - GENERAL THOUGHTS

### 2.1 What kinds of break are on offer in your area for people with dementia?

A. & B. Rothesay - Mon - Fri day care 9-6, and 1 respite bed on Island. Apart from a very small number of home support hours from Alzheimer Scotland available in Helensburgh, there are no Alzheimer Scotland services in this area. Other options are not known to Involvement officer: past verbal reports suggest that in many areas there is very little available.

E. Ren. Respondents unfamiliar with current resources. Area does have 2 specialist dementia services offering day and home support, 1 service offering support to younger people with dementia and a befriender service which also specializes in support to people with dementia including an extension to project to support people as volunteers themselves. Overnight options are not known to Involvement Officer.

Inv'clyde Carer response: *Respite - not used as yet. William st 5 days a week - more on request. 30 mins carer help 4 mornings a week, 30 mins care help 7 evenings a week to administer medication*

There is a specialist service providing day care and another home support. Detailed other provision not known to Involvement Officer

Ren. Respondents described 3 home support services, small amount of overnight in own home (emergency and planned) with discussion for expansion, specialist and general day care, one specialist dementia care home/respice unit, good provision from day hospital and older adult mental health team and some provision within generic mental health resource. Nothing known specifically for younger people or other than care home setting for longer stays. Carers group also remembered holiday home Alzheimer Scotland used to run (St Johns) and were sorry no longer available.

W. Dun. Small amount of home support from 3 sources, short break service (carers centre) gives 4 hrs per week which can be banked for an overnight, day opportunities at Elm Centre (also have group for younger people) and general day care from local authority, lunch clubs, day hospital, No overnight provision other than mainstream residential respice. Very small amount of nursing home respice.

Unknown Carer response: *Day centre and Respite on regular basis*

**Comments:** *I am aware that there are different day care places but most of them are mixed with dementia and people without. I feel that Riccartsbarr only being for dementia, the staff are more aware and caring of their needs (Carer: Ren)*

*Nursing home respice (can be specialist EMI) not always available - just if permanent beds not taken up (Prof. W Dun.)*

## 2.2 Tell us about what works really well for you and why?

### CARERS

- *My husband attends Riccartbar (Alz Scotland specialist day care) 3 days a week and as his wife and carer I find this very beneficial both for him and myself. I feel he is much more alert and stimulated when he returns and of course gives me time (Ren)*
- *Respite - carer elderly - 86 years old - illness overwhelms (Ren)*
- *Befriender takes my husband on outings. Befriender dependable, calls regularly, is flexible and very understanding which is much appreciated (Ren)*
- *Now that my wife's Alzheimer's is in the severe stage, I find that the 2 days she is at the day centre good for me. Home carers are also excellent (Ren)*
- *A person who takes an interest in V and V is clearly happy (Ren)*
- *Any break works well, as a carer I feel relaxed and not as tense. (Ren)*
- *Day service breaks give time for carer to get things done (Ren)*
- *My husband goes 2 days to Alzheimer's day care . A support worker goes out with him from 12.-4pm to allow me to attend carers support group (only once a month) but I have the time every week. (Ren)*
- *The attention we get from Riccartbar and the daily assistance from the social work home help ladies. The all round cheerfulness of these people. (Ren)*
- *For our part, we had a lot of help from CPN and latterly we had help from the fast response team, social work sitter-in and of course trips out (day care) arranged by Riccartbar. In addition, we had a week's respite at Adams House (specialist dementia care home/respite) (Ren)*
- *My wife gets good long breaks about 6 times a year which suits us. She could get more but the present arrangement is good. (Ren)*

**Renfrewshire Carers Group** - Home support -Reassuring - knew where people were and that they would be safe. (e.g. of wife dropping husband at church club where paid carer met them and then brought him home).

Day hospital good - keep the person until another day care is available after all the tests are done.

Adams House - highly respected - praised by those who had used it Nothing too much trouble - staff excellent. However, not available to person under 60.

One carer described how social worker had helped arrange place so that her parents could move into long term care together (had different care needs). Although some people were saying how they would be put off using a care home for respite this person's experience was different - the home had given her parents extra independence and the good quality care left her feeling they were happy and cared for allowing her to feel happy that the decision had been a good one. We should not just dismiss care homes - they can be a good option. Having a good social worker makes a difference. Present one always gets things promised done - even if it takes a little while.

### **West Dumbartonshire Carers Group**

Elm Centre - settled and stimulated whilst he's there.  
Befriender works well - short break works well

## PROFESSIONALS

- *Day care offer support to both client and carer (Ren)*
- *Our assessment and response team allows us to become quickly involved in obtaining appropriate inputs from the above choices. We are frequently asked to arrange respite to allow carers to plan holiday breaks (and our record is good) (Ren)*
- *Respite by way of it going into their home because that is where the person is. Need to have weekly respite as well as opportunity of residential/nursing for overnights. Important to have respite in the home for those who don't like a social communal setting (W. Dun)*
- *Day opps work well - stimulation and person centred activities mean person is well supported. This in turn helps the carer. (W. Dun)*
- *As a worker, I feel respite within own home would be best- however; this is not readily available in our area. Respite within a care home can cause additional confusion, but carers are comforted by knowing 24 hours care is provided. (W. Dun)*

### 2.3 Do you feel this is enough?

| NO                                    | 48% (14) individuals                               | YES                                      | 28% (8) individuals           |
|---------------------------------------|--|--|-------------------------------|
| 28% (8) (Carers<br>(6 Ren, 2 unknown) | 21% (6) (Professionals<br>(1 Ren 4 W Dun, 1 A & B) | 24% (7) Carers<br>(5 Ren, 1 Inv 1 A & B) | 3% (1).Professionals<br>(Ren) |

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• <i>I feel there should be more outreach working (A &amp; B Prof)</i></li> <li>• <i>Could do with more support (Ren Carer)</i></li> <li>• <i>It doesn't happen much at all (W Dun Prof)</i></li> <li>• <i>Require more places for specialist day care (W Dun Prof)</i></li> <li>• <i>Befriending services badly need for more additional support (W Dun Prof)</i></li> </ul> | <ul style="list-style-type: none"> <li>• <i>At the moment although if it wasn't for my daughter and a friend I would feel I could do with help if I wanted to go out at night (Ren Carer)</i></li> <li>• <i>.but one carer lacks the skills (Ren carer)</i></li> <li>• <i>Everyone will claim they could do with more resources, we seem to respond effectively to current demand (Ren Prof.)</i></li> </ul> |
|--|--|

**W Dun. Carers Group** were pleased with the facilities on offer. This was not asked of Ren Carers Group

## 2.4 Are there times you have needed a break and it has not been available?

| <b>YES</b>                                   |                                     | <b>NO</b>  |  |
|--|-------------------------------------|--|--|
| 41% (12) Individuals                         |                                     | 31% (9) Individuals  |  |
| 28% (8) Carers<br>(1 E Ren, 5 Ren, 2 Unk'wn) | 14% (4) Professional<br>(all W Dun) | 31% (9) Carers (0 Professionals)<br>(1 A&B, 1 Inv 6 Ren 1 Unknown) |  |

- *Sometimes difficult to find places in emergency (E Ren Carer)*
- *I find it very difficult to get booked respite. I have been told that no nursing home will take a booking in advance for respite. I have 2 young children, and trying to book holidays around school holidays is not so easy. (Ren Carer)*
- *I find it very stressful trying to arrange holidays and respite for my mum. There are not so many places in "good" nursing homes available and now I am no longer going to use respite - infact - I don't know what I am going to do getting holidays now. (Ren Carer)*
- *Carer was unwell and nowhere was available for respite (Ren Carer)*
- *I always need a break - I simply cannot plan it, life is so immediate - I am 84 (Ren Carer)*
- *There have been times when clients have had to wait, so yes (W Dun Prof)*
- *There have been times when I can't get people the services they require, especially Alzheimer Scotland home support hours (W Dun Prof)*
- *Yes, responding to need (W Dun Prof)*
- *At times I need to secure respite outwith our area due to lack of availability. Clients and carers are not always happy with this. (W Dun Prof)*

- *No as I pay private help as requested (Inv Carer)*
- *Not so far but as time goes on who knows. This last 2 years have worked out well but as my wife's Alzheimer's has got worse this looks like this could happen. (Ren Carer)*

### Renfrew Carers Group

**YES** One carer looked after both elderly parents - one who had dementia. This year it had been much harder to organise his holiday break, as both people needed care. Tend to rely on other family

### W Dunbarton Carers Group

**YES** in an emergency it is hard to get respite

**2.5 To your knowledge are limits being applied that stop you getting the respite you need (e.g. lack of funding, long waiting lists, maximum number of weeks allowed, lack of staff)? If so what affects you?**

| <b>YES</b>   | 55% (16) individuals                               | <b>NO</b>  | 18 % (4) individuals |
|--|--|--|----------------------|
| 31% (9) Carers<br>(1 A&B, 1 Inv, 6 Ren, 1 unknown) | 24% (7) (Professionals<br>(2 Ren 4 W Dun, 1 A & B) | 18% (4) Carers (0 professionals)<br>(Inv A & B, 3 Ren 1 unknown) |                      |

- *Only 1 bed at Thompson Court at the moment so could be limited (A&B carer)*
- *I had to go on a waiting list for carer help (Inv carer)*
- *Long waiting lists/lack of funding means that my husband can only go to Riccarton Centre twice weekly (sometimes 3 times if places available) (Ren Carer)*
- *Lack of staff (Ren Carer)*
- *Unwilling to try something new! I was offered day visits at Alzheimer care centre but my husband feels that 2 days already at council day centre was sufficient (Ren Carer)*
- *Not so far with Alzheimer Scotland who have been brilliant. Renfrewshire carers - I applied April 06 for one night a fortnight, I am still waiting for them to call to my home to do an assessment, last time I was in touch it will be another 4 weeks - Lack of funding? Lack of staff? (Ren carer)*
- *Lack of funding and finding good nursing homes, you just can't get respite in "good" places. (Ren Carer)*

- *No assistance is good (Ren carer)*

**Renfrew Carers Group**

**YES** New emergency respite - Rumour was that criteria for service very strict - person had to have a social worker and be receiving care from social work - if this were true - it would rule out anyone in earlier stages of condition who would not be in receipt of personal care at present.

**West Dunbarton Carers Group**

**YES** All of these are restrictions for one carer from Argyll & Bute.  
Maximum number of weeks.

- *J had a befriender, but unfortunately this did not work out (Ren Carer)*
- *Lack of funding (Unknown carer)*
- *Lack of respite beds means at times long wait for respite (A&B Prof)*
- *Lack of funding, lack of resources, maximum no of weeks, lack of respite beds (Ren Prof.)*
- *All of the above may impinge on referrals and our responses. These things are not necessarily applied, but they do exist in practice. (Ren Prof)*
- *Waiting for funding to be allocated to enable respite - from one council more than the other (W Dun Prof)*
- *Mainly lack of funding. People with complex needs can require a very large package of care which means others get less and have to go on a waiting list (W Dun Prof)*
- *Long waiting lists and lack of staff (W Dun Prof)*
- *The main difficulty is lack of availability in the area (W Dun Prof)*

## 2.6 If you have turned down or stopped using a respite type service for any reason, please say what put you off

10% (3) Carers said **NO** (A&B, Ren, Unknown). 20% (6) respondents (3 carers and 3 professionals) gave comments indicating they had:

- *Alzheimer befriending. Person too young - nothing in common. (Ren Carer)*
- *My wife needs 24 hour 1-1 care. The local place could not cope. (Ren Carer)*
- *My mum ended up in hospital after 2 weeks in respite whilst I was on holiday, due to dehydration etc. (Ren Carer)*
  
- *People have brought or taken their loved ones home because of environment. (W Dun prof)*
- *People are often put off if it takes the person with dementia a long time to settle after being away in respite (residential/nursing). Also people get annoyed when clothes are lost and staff seem not to care. (W Dun prof)*
- *One client distressed as her husband had an accident whilst in care home respite and she was not notified. Neither was I as Care Manager. Incidents like this are few but cause much distress. (W Dun prof)*

## 2.7 If you could design the ideal short break/respite service, what would it be like?

### CARERS

- The present respite service (Thompson Court) is very good **(A&B)**
- Something with easy travelling distance would be ideal. Carers available, if necessary to help with outings or to enable the carer of the person suffering from dementia to have a short break to shop or visit places of interest. **(E Ren)**
- Someone staying with my mother 24 hours a day so that I could fully relax without worry. This would be in her own home as she refuses to go anywhere else. **(Inv)**
- I think sometimes if an odd overnight stay was available it would benefit the carer. Having a night without any duties and without any worries. **(Ren)**
- Midweek breaks, long weekend breaks, annual 7-10 days, variety every month **(Ren)**
- A weekend on my own with someone staying in my home with my husband. **(Ren)**
- MS people have a place in Largs, geared up with caring staff that both carers and their partners could have a short holiday away from home but still together for 3-4 days. I feel this would be good for both of them. Carers would be able to relax and having the right staff would make this a good respite service. **(Ren)**
- Be like a dream **(Ren)**
- My only experience is Riccarton and the staff there are very good. More places like that but designed with bedrooms to accommodate people overnight. **(Ren)**
- Can't even countenance leaving him at the moment. I think he would be hurt if I did and I wouldn't want to go away on my own at the moment. Perhaps if there was a hotel/B & B with other carers there! **(Ren)**
- Daily visit to care centre, including weekends with overnight stays in own home with carer or daily visits to care centre with weekend AND overnight stays in own home with carer. **(Ren - presently gets M-F day care)**
- Stimulations - walks, dancing etc. **(Ren)**
- For there to be homes especially for respite. Staff to be trained on dementia and everyone to get a fair share of respite **(Ren)**
- A club where J could go on his own for a few hours, he is very reluctant to do

- anything without myself being present. **(Ren)**
- The present Adams House 7-10 day break is ideal at this point of time. **(Ren)**
- Flexible response both in terms of where things are offered and also availability at short notice **(unknown)**

#### **Renfrew Carers Group**

Staff are the most important thing - they need to know about the condition as well as be caring people. You get a good rest when you know the person is happy and supervised. Those stating a time preference felt during day more useful than evening or overnight.

#### **West Dunbarton Carers Group**

5-day day care in Elm Centre type facility, weekend respite once a week, going away for a week at least once a year and an emergency type of respite. One person would like to be able to take a break with the person with dementia

### **PROFESSIONALS**

- Being cared for in one's own home, I believe would be ideal - having your belongings and familiar surroundings is important to a person with dementia.
- Volunteer/befriending service - more specialized dementia beds **(Ren)**
- I don't feel there is much wrong with our service/response, but customers/carers may disagree, and there may be many types of potential care arrangements with which we do not get requests/referrals. **(Ren)**
- Small, ground level, tailor-made. Good ratio for staff to resident. Staff with knowledge, understanding and experience in caring. **(W Dun)**
- Flexible. Home and residential overnight in people's houses if desired. Specialist for people with dementia (none of our local authority homes have staff with specialist training). More Alzheimer's Day opportunities which is tailored to meet individual needs and interests and is morning, afternoon and evening. **(W Dun)**
- Day opps like that at the Elm Centre **(W Dun)**
- Client centred, choices of menu, personal service, bright, airy and clean, observe dignity. Space if I wanted it. Private sitting room for visitors, refreshments for visitors, good communication and information, trained staff, proper equipment. **(W Dun)**

## PART 3

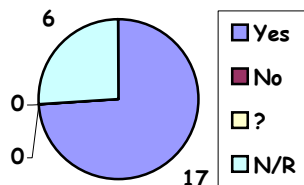
### OVERNIGHT SHORT BREAK EXAMPLES

Respondents were asked to comment on whether they would use or had used specific models of care. The examples have been arranged in order of carer positive comment. Responses from carers and professionals are shown separately to indicate if significant differences. There were probably 2 main areas of difference. Many carer respondents were very much in favour of places they could take a break together with the person they cared for which was least preferred option with professionals. The fostering type model was only favoured by the W Dunbarton Carers Group and was least popular with other carers. This was a positive option for half the professional respondents. Outside this survey, people with dementia have rated this option highly.

The carer group responses have been counted with individual carer ones but counted as 1 extra carer each, so this section now assumes 23 carers instead of 21 for display purposes.

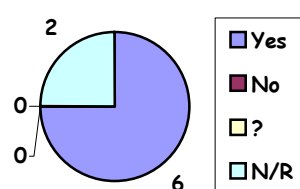
#### 1. Stay in a small specialist dementia unit used only for short breaks

##### Carers



Both Carer Groups said Yes

##### Professionals



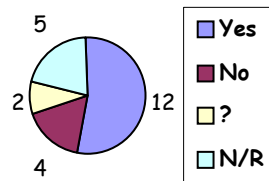
##### Comments

- *Would have liked to try Adams House - got to be 60 or over. (Carer)*
- *This would be ideal - is there any such place? - Would be very useful. This sounds better. Could be useful. Sounds good (Carers)*
- *Could be very helpful for cover to attend family illness, funerals or happier events (Carer)*
- *Ideal scenario better by far than care home. First Class (Profs)*
- *Don't have any experience of this but think it would be good (Prof)*
- *Can be good experience. Good for carers but short breaks can be confusing for client (Prof)*
- *This would be the best way of supporting person with dementia (Prof)*

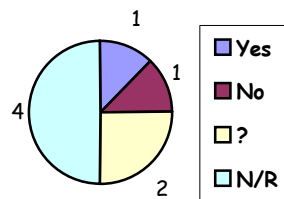
**Renfrew Carers Group** - People said they would not feel as guilty using something like this that was purely for short breaks. I described somewhere where there was a separate respite unit on the same grounds as a residential home but the 2 were kept separate. People were not put off by it being on same site. Were put off though by feeling of being in a very large building. The split site option had benefit that if person did move into permanent care - they would already know many staff and there would be some familiarity about the place

## 2. Would you want to take a break together (person with dementia and family carer) or not?

Carer



Professional



Both carers groups said Yes

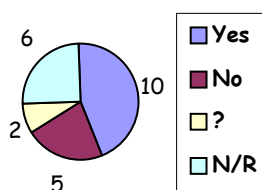
**Renfrew Group** - Several people liked idea of somewhere you could go together with help around - although you were not separated it would still make you feel you were having a break from usual caring.

Comments

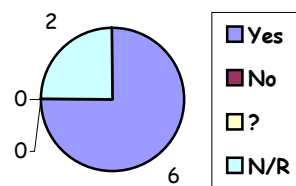
- My wife always wants to go home after 30 minutes. (Carer)
- At present my holidays are with my husband but I am getting to the stage that a break alone would be lovely (Carer)
- If there could be somewhere dementia friendly hotel/B&B where allowances were made for behaviour etc (Carer)
- Provided there was help available to allow family cover some free time. (Carer)
- I already take my mother on holiday to visit family and friends (carer)
- A break away from the person you care for is good but only if the carer can have peace of mind (carer)
- At the beginning of my Mum's illness - but not now. (carer)
- This would be ideal (Carer)
- Maybe not practical for professional reasons (Prof)
- Most carers need time to themselves - I think few would consider this option (Prof)
- Very much depends on the stage of the illness as it can be difficult to do this in the later stages (Prof)

## 3. A paid carer to stay in your own home whilst family carer went elsewhere

Carer



Professional



W Dun group said No

Renfrew Group said maybe

**Renfrew Group** - Might be used for a specific family event or to organise a golfing break. More popular for something arranged rather than on a regular basis.

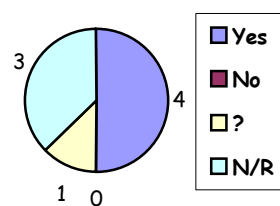
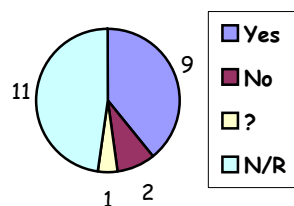
Comments

- Would suit my husband as he would not want to stay in a care home, I would use this type of service as my wife prefers to stay in her own home, This would have been useful (Carers)
- Possibly, if necessary, Could be useful if respite not available (Carers)
- This is a good option as the patient is not disorientated by moving to a new environment (Carer)
- My Mum may have used this if she could have got a carer who already knew my Dad and was trained in dealing with dementia. (Carer)
- No, I would not feel comfortable with this (Carers)
- Popular option, not readily available. Same worth as specialist option, definitely. A very good service, providing for the needs of individual one to one. Ideal (Profs)
- Carers appreciate this service, could do with more workers (Prof)
- In emergencies only, and must be with staff who know the person well (Prof)

#### 4. Funding to book your preferred break with a service giving information about options, finding a carer (a short break travel bureau)

Carer

Professional



Both groups said yes

#### Comments

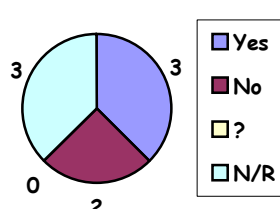
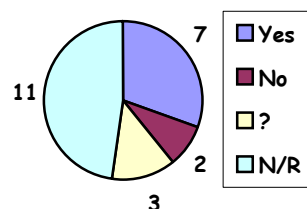
- Somewhere like the MS place good or the B&B with a carer. Funding with a top up from client/carers if needed (Carer)
- This would be good. Sounds interesting. Could be useful. Excellent idea, very useful to make arrangements for family events (Carers)
- It would have to be appropriate accommodation and with trained people to do the caring (Carer)
- This is a good idea if it would work. A possibility. Gives a greater choice of options. Would be ideal - know lots of clients and carers would like this - more independent. (Profs)

**Renfrew Carers Group** - This was a very popular choice - several people thought they would use it. Again would top up funds.

#### 5. Stay in a residential or nursing home

Carers

Professionals



Dunbarton Group said Y  
Renfrew Group No

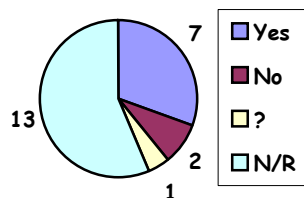
#### Comments

- I don't think I would like to use this, Probably not, apart from emergency (carers)
- I found that my Mum could no longer use residential homes, then the problems regarding respite started (Carer)
- My mother refused to go even for 3 days (Carer)
- Last option, if others available (Prof)
- Would be better if it is specialist dementia people trained in this area (Prof)
- Can be a positive experience, qualified staff and good care (Prof)

**Renfrew Carers Group**- felt guilty about going somewhere and leaving person behind - felt as if you would rather take them with you. Also felt person might think they would not be coming back home. *Felt not at that point yet.* We discussed what this meant - is respite something you have to wait until you are at breaking point to accept or is it something designed to stop you getting at breaking point. From the discussion it was felt that it should be something you had early on but that feelings of guilt at leaving the person or not liking the choices on offer stopped you.

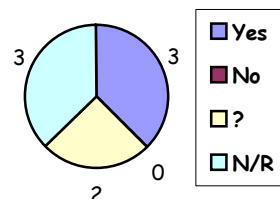
## 6. Somewhere for a carer to stay whilst person with dementia cared for at home

### Carers



Renfrew Group said yes  
W Dun group said no

### Professionals



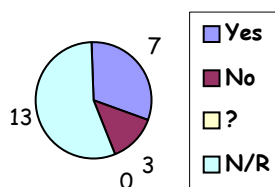
### Comments

- *If I had a carer staying at home with my wife, I would certainly find somewhere to go for a short break (Carer)*
- *Good option because there is more security in familiar surroundings*
- *The caring would have to be good. Might be good. (Carers)*
- *Would probably not have used but would be good for carers without family support (Carer)*
- *Not for everyone (Prof)*
- *Definitely. Ideal. Could be beneficial - less distressing but very seldom an option in our area (Profs)*

**Renfrew Carers Group** - Like a crash - pad. Might be useful if for example you had gone a while without getting sleep. Would prefer to be given a stay in a B&B/hotel though!

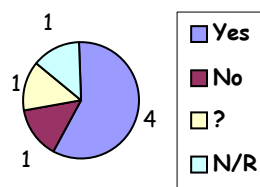
## 7. Going on a group break supported by people with dementia knowledge

### Carers



W Dun Group said Yes  
Not discussed by Renfrew

### Professionals



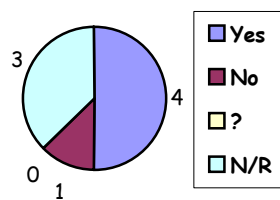
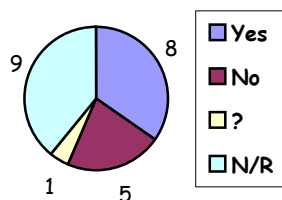
### Comments

- *I don't think this would work for me. Never - not my idea (Carers)*
- *Possibly - maybe in the future (carer)*
- *Attractive. Could be successful if members of group already knew each other. A group break sounds good because the person with dementia could be with familiar people. (Carers)*
- *Not for everyone (Prof)*
- *Definitely. Know people who have benefited from this. Would be great but I don't know of this service in our area. (Profs)*
- *The idea of going about in a group I feel draws attention to disability (Prof)*

## 8. Using a B&B, caravan or holiday type setting where could take a paid carer or support on site

Carers

Professionals



### Comments

- *Prefer MS model - would try B&B with paid carer support (Carer)*
- *Too old. No I don't think this would work (Carers)*
- *Sounds attractive. A good idea. A place husband and wife could go with a carer would be good. (Carers)*
- *Not keen on this option (Prof)*
- *Definitely. Allows a person to visit favourite places. Few and far between but would be worth considering. (Profs)*

Renfrew Group said Yes

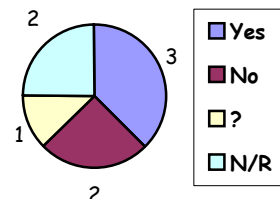
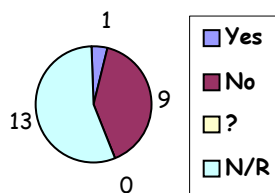
W Dun group said Yes and no

**Renfrew Carers Group** - loved idea of *dementia friendly* establishments. E.g. ordinary B&Bs or hotels perhaps with staff trained about being dementia friendly perhaps made some changes to their accommodation like good signs and labels up, easy to use facilities etc. Somewhere you didn't have to keep explaining - help just offered or you could ask. Perhaps places could choose to be registered as a short break facility with a local authority - they would be checked and staff trained. You could then either book them yourselves if there were somewhere you could get a list of registered establishments or they could be used as options by local authorities to provide respite. The family carer might go for a joint break or where appropriate, a paid carer go with the person with dementia. The money used for a care home could be used (might only be a long weekend rather than a week) to fund it. Thought many places would have quiet times of year that might make it a popular option for them.

## 9 Fostering type model - person with dementia stays in someone else's home - feel of staying with a friend

Carers

Professionals



### Comments

- *This would only agitate and frustrate my wife - she would prefer to be in her own home. Not keen on this option. Don't fancy this. Might have caused confusion so probably would not have used. My Dad always felt more secure in his own home - so not such a good option (carers)*
- *Has same worth as specialist option. Could be good if people are well matched. Ideal. Not familiar with this service provision but seems it could be beneficial (Profs)*
- *Too confusing for person with dementia (Prof)*

W Dun Group said Yes

Renfrew group said No

**Renfrew Carers Group** would all members of the family be vetted? - what about social callers to the family home? If the person combining it with their own family commitments would they not put their own family needs first and the person be neglected? If foster carers providing a year round service as a paid job - when did they get a break?

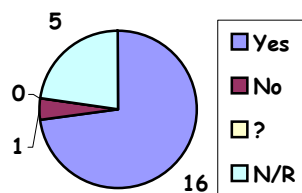
## PART 4

### SHORT BREAKS - DAY/EVENING EXAMPLES

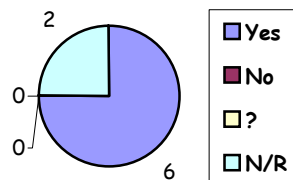
Respondents were asked to comment on specific models of support. The responses are compiled in the same way as for overnight stays. Responses were consistent between carers and professionals in this section. The W Dunbartonshire Carers Group has been incorporated into the results, again as an additional carer. The Renfrew Group did not discuss this section.

#### 1. Person with dementia going to a regular group/centre with others (state useful times/days in comments)

Carers



Professionals



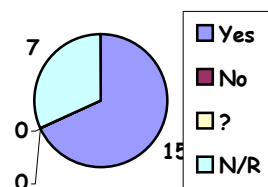
#### Comments

- *Many described service and added - Would like more. Daytime best. If it were a whole day I feel I could do something worthwhile and not be rushed. I hope that doesn't sound selfish. Seems to enjoy it. It was great - he enjoyed it and felt safe there with people who understood him. Excellent. Absolutely essential service. At least twice a week for several hours provides a useful break for carers. (Carers)*
- *Never works. (Carer)*
- *Good support. Excellent if person is socially inclined - mornings afternoons and evenings. Most used service - weekends seem to be most useful time for carers. More availability at weekends and evenings. (Profs)*

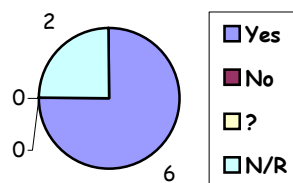
W Dun Group said Yes

#### 2. A carer staying in your house for a few hours (family carer may do something indoors or go out)

Carers



Professionals



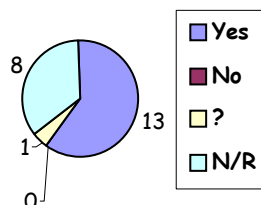
#### Comments

- *Works very well. Would use. Useful for theatre nights etc. Very good option as it allows the carer to give time to their partner. Mum used and really appreciated it although it would have been better if the person had been trained in dementia (Scot Nursing) (Carers)*
- *Definitely. I have many service users who want this but there are not enough hours to go around. Clients and carers find this a good experience. Break for carer and maintains routine for person with dementia (Profs)*

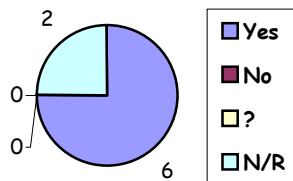
W Dun Group said Yes

### 3. Someone taking person with dementia out for a few hours to follow interests/ activities

Carers



Professionals



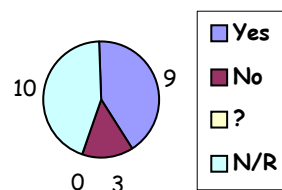
#### Comments

- *Good option, Might work if second carer were known. Would use. Could be useful. Mum used this option - better because Alz Scot people are trained and I certainly felt a lot more confident with that arrangement (Carers)*
- *Good option, Definitely. Excellent - especially if person prefers one to one rather than group activities. This has been found to be a good experience. Break for carer and stimulation for person with dementia. (Profs)*

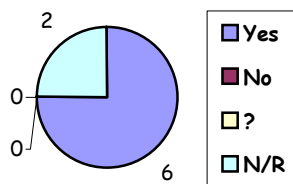
W Dun Group said Yes

### 4. Organised social events and outings

Carers



Professionals



#### Comments

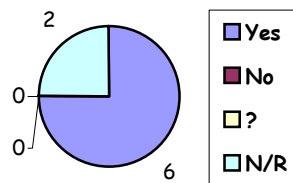
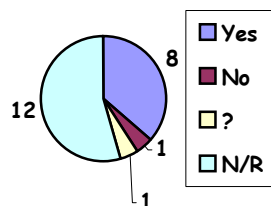
- *Would use. Ideal. Sounds good. My Dad enjoyed outings but it was better when it was geared to his interests. (Carers)*
- *Wife cannot follow music, books, TV plays. Probably would not have used unless it had been of particular interest to my father.(Carer)*
- *This happens to some degree. Good to offer these opportunities where carers don't have to explain but people understand. Clients enjoy these events Carers can join in but some use time to themselves. (Profs)*
- *One - one - not large group (Prof)*

W Dun Group said Yes

### 5. A drop in - stay about 2 - 3 hrs max (state useful times/days in comments)

Carers

Professionals



W Dun Group said Yes

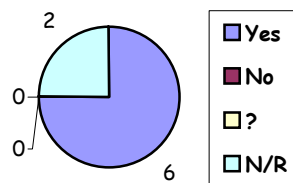
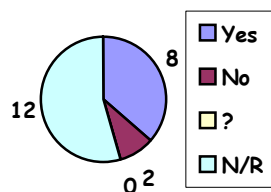
#### Comments

- *Useful time - 10.am-1pm. This would be good for evenings. Probably useful for shopping. Would have been good because it would be flexible. My Mum was short of things to do with my Dad when on their own. (Carers)*
- *Could perhaps be useful in an emergency but slightly longer breaks more beneficial to carer.(Carer)*
- *Depends on state of disease process, some can be upset and aggressive in new surroundings. Routine is what they are calmest in. (Carer)*
- *Again - occurs just now. Excellent, especially if near shopping centres so carers can get shopping. Also people can pick times that suit them. Mornings and afternoon. Again widely used - allows carers and clients to plan. No weekend access. Could be for person with dementia and carer - afternoons. (Profs)*

### 6. Befriending volunteer to support person with dementia in activity or to volunteer themselves

Carers

Professionals



W Dun Group said Yes

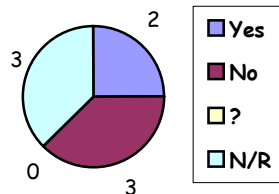
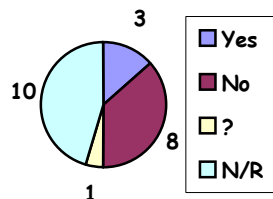
#### Comments

- *Some described how support worker does this. Sounds like a good idea. Befriending is good if chosen carefully (Carers)*
- *Much needed. Excellent. Badly needed service not available in our area - beneficial to all older people. Only if volunteers are well trained in all aspects of dementia. (Professionals)*

7. Person with dementia going to someone else's home, maybe with another person

Carers

Professionals



Comments

- *Not likely - wife asks to leave. Don't like this. Could cause confusion but may suit some people. Only if the person is really well known to the carer and the patient likes them. Not sure - it may make the person with dementia feel uncomfortable (Carers)*
- *Can be very friendly, homely and non institutional. Not used often - resulting in isolation for carers. Too confusing for person with dementia (profs)*

W Dun Group said both Yes and No

Jenny Douglas/ 24.10.06