



Evaluation of Flintshire Admiral Nurse Service

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Evaluation of Flintshire Admiral Nurse Service

Executive Summary

1. Admiral Nurses are specialist mental health nurses who aim to improve the life of people with dementia and their carers by working primarily with the carer offering information, support, therapeutic interventions and education. Admiral Nurse services are supported by the charity **for dementia**, and are available in a number of areas of England.

2. The Flintshire Admiral Nurse Service is the first of its kind in Wales. It was established following a joint initiative between the Alzheimer's Society, **for dementia** and DSDC Wales, which resulted in an Admiral Nurse Trailblazer being employed by Flintshire LHB, using WAG Wanless funding, with the remit to explore the potential for bringing the Admiral Nurse model to North Wales. Big Lottery funding was obtained, expected to be matched for a 3 year period by WAG Carers' Mental Health Grant funding from Flintshire County Council (but in the event, matched funding for the third year was not granted). The stated intention was for the service to be mainstreamed by Flintshire LHB at the end of 3 years, from funds becoming available from Flintshire's disinvestment in services from Conwy & Denbighshire.

3. The service has comprised a Clinical Lead (Band 7, in post March 2007 – May 2009), an Admiral Nurse (Band 6, in post May 2007 – present) and an administrative team secretary (in post July 2007 – present). The nursing staff have been employed by **for dementia** rather than by the host organisation (North East Wales NHS Trust and its successors), whilst the team secretary has been employed by the NHS, who are reimbursed by **for dementia**.

4. From March 2007 to August 2009, 151 referrals were recorded to the service, from a wide variety of sources, with psychiatrists, CPNs and Social Workers each providing around 20% of the total. Although the Admiral Nurse model of working allows for long-term involvement, throughout the care-giving journey, it had proved possible to discharge over half the carers who had been taken on. In August 2009, the Admiral Nurse had a case-load of 39 active cases, with 23 receiving intensive input, 8 receiving maintenance input, and 8 in a holding pool, where input can be rapidly made available if there is a change in the care-giving situation. There was a waiting list of 18 carers at that time. Around 10% of referrals related to a person with dementia under 65 years of age. Around 20% of the current active cases involve joint working – with a CPN, Social Worker, Memory Service nurse, or some combination of these; in every case, this reflects the complexity of the case.

5. Seven family care-givers who have received the Admiral Nurse service were interviewed individually, and provided an extremely positive evaluation of the service

received. Carers spoke highly of the accessibility of the service and the importance of the specialised knowledge of the nurse.

6. A number of professionals (10) were also interviewed, or provided comments in writing. These included CPNs, psychiatrist, Memory Service, Social Workers and NEWCIS, the voluntary organisation providing support to carers in the area. In general, there was a great deal of appreciation of the work undertaken, and the extent to which it eased the load on other professionals, who were now holding off making referrals in view of the uncertainty regarding the future of the service. Some referrers are continuing to call for advice on clients despite the service being closed to referrals.

7. The evaluation clearly indicates that the Admiral Nurse service has become a valued component of services for people with dementia and their families in Flintshire. If it closes, it will be missed by carers and professionals, some of whom sensed that an opportunity will have been missed to build on the learning from this project in developing similar services across other parts of Wales. A number of sources reflected on the teething problems in the early days of the service and the difficulties apparently emanating from the team being employed by, and receiving supervision from, an external agency, leading, for example, to practical issues with furniture and organisational issues regarding the relationship with the CMHTE and access to case-notes.

8. A number of key issues were addressed with stakeholders in order to inform potential ways forward:

- Where is the service best located organisationally? In Social Services, NHS or third sector?
- How important is it that the service is provided by a nurse?
- What should the balance be between case-work and consultancy / training aspects of the Admiral Nurse role?
- To what extent should the Admiral Nurse work with the person with dementia, if the carer is the primary focus?
- How best should Admiral Nurses work with CPNs?

Several of these issues had been the focus of Steering group meetings and interventions over the life of the project, with, for example, it being felt at one point that there was too much emphasis on case-work and not enough on consultancy, to the extent that the Clinical Lead was instructed to carry out less case work. Elsewhere in the UK, typically the pressure has been to increase the number of carers seen.

9. Definitive answers to these issues may not be possible, and in several instances there were arguments for and against. but there was certainly a broad consensus that the service would be best located within the NHS, linking closely with, or forming part of, the CMHTE and that mental health nurses are best placed to have the

specialist knowledge and skills, including the delivery of psychosocial interventions for the care-giver, that is needed, and that this fits well with NICE-SCIE guidelines on dementia care and draft WAG targets for the NHS on dementia. There was clear evidence that the service has had an impact not just on the carers receiving it, but also on the broader system. Social workers commented on their learning from the Admiral Nurses in the context of cases, and judged this of greater value than emphasising consultancy work. CPNs felt the Admiral Nurse model lent itself well to carers with complex needs, and valued the possibility of longer-term involvement that could be provided. CPNs reported that when working jointly, the current Admiral Nurse was careful to ensure the CPN was involved in issues directly related to the person with dementia. In the majority of cases, involvement of the Admiral Nurse alone is sufficient to address the needs of both carer and person with dementia, which are met primarily through working with the carer.

10. The Admiral Nurse model is evidence-based, and, having worked through some challenging teething difficulties, the current Flintshire project does now provide an excellent launch pad for future working. It is recommended that the service continue within an NHS context, integrating with the CMHTE, to ensure overlap of cases only where the complexity of the clinical situation necessitates this, allowing good local management arrangements, whilst continuing to benefit from the professional development supervision which **for dementia** offers to all Admiral Nurses. The service would then continue to be carer-focused, but this does not mean that it should be blind to the needs of the person with dementia, and the Admiral Nurse's role in working with the carer in relation to these needs is a vital aspect of cost-effective evidence-based psychosocial interventions. It would appear from the referral rates and waiting lists that 2 nurses are required to provide this service to Flintshire. It is recommended that rather than setting down specific expectations for the amount of time spent on work other than direct case-work, the range of evidence-based interventions for carers be allowed to develop to include, for example, group interventions, where appropriate and inputs to the development of related services. This balance may be revisited if and when there is investment in expanding Admiral Nurse services to provide input across a broader geographical area in North Wales.

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Evaluation of Flintshire Admiral Nurse Service

Purpose

This report presents and discusses findings of an independent evaluation of the Flintshire Admiral Nurse Service, commissioned by the Steering Group for the service. The evaluation was undertaken by members of the Dementia Services Development Centre, Bangor University (DSDC), and the remit was to produce, with a turn-round of 2-3 months, an overview of the service and its achievements, including its impact on services for people with dementia and their carers more generally, in order to provide guidance for future service provision.

We would like to thank all those involved with the evaluation for their time and input. In view of the small size of the service, the identity of the Admiral Nurses involved cannot be meaningfully anonymised.

Introduction

Admiral Nurses are specialist mental health nurses who aim to improve the life of people with dementia and their carers by working primarily with the carer offering information, support, therapeutic interventions and education. Research supports the model of Admiral Nurses (AN), where the caregiver receives on-going input and support, rather than the focus being on short-term assessment and discharge, in terms of care-giver distress (Woods et al., 2003). ANs provide specialist help designed to meet the health, emotional, and practical needs of family carers. The Admiral Nurse Service (ANS) prioritise carers with complex needs who are having difficulty coping with their caring role. They aim to facilitate the healthy management of the illness, prevent crisis and reduce the risk of carer breakdown. Interventions help the main carer and family unit to stay well by teaching them how to adopt healthy coping strategies during their journey with the illness (Flintshire Admiral Nursing Operational Policy, 2007).

Another role of the Admiral Nurse is to raise awareness and provide education and training to professionals working with people with dementia in order to improve or teach new skills in care giving. The charity **for dementia** leads the development of Admiral Nurse Services and of Admiral Nursing, with a growing number of Admiral Nurse teams working within, and employed by host organisations around the UK (Clare, Wills, Jones, Townsend, & Ventris. 2005).

The Flintshire Admiral Nurse Service (FANS) is the first of its kind in Wales. It was established following a joint initiative between the Alzheimer's Society, **for dementia**, and DSDC Wales, which resulted in an Admiral Nurse Trailblazer being employed by Flintshire LHB, using WAG Wanless funding, with the remit to explore

the potential for bringing the Admiral Nurse model to North Wales. Big Lottery funding was obtained, expected to be matched for a 3 year period by WAG Carers' Mental Health Grant funding via Flintshire County Council (but in the event, matched funding for the third year was not granted). The stated intention (recorded in minutes of the Trailblazer Steering Group) was for the service to be mainstreamed by Flintshire LHB at the end of 3 years, from funds becoming available from Flintshire's disinvestment in services from Conwy & Denbighshire.

FANS is overseen by a steering group which comprises representatives from key stakeholders from the Older People's Mental Health Services in Flintshire, and family carers. The host organisation was the North East Wales NHS Trust and its successors, initially the North Wales NHS Trust and from 1st October 2009 the Betsi Cadwaladr University Health Board (BCUHB). FANS is based in Aston House, Deeside.

The service has comprised a Band 7 Clinical Lead, who was in post from March 2007 until May 2009, a Band 6 Admiral Nurse, in post from May 2007 until present, and an administrative team secretary, in post July 2007 to present. The nursing staff have been employed by **for dementia** rather than the host organisation whilst the team secretary has been employed by the NHS, who are reimbursed by **for dementia**.

Evaluation – aims and methods

The aim of this evaluation is to present evidence of the work the Flintshire Admiral Nurse Service have undertaken thus far, and its impact on services more generally. The evidence takes the form of summary statistics of contact with carers and consultancy tasks, vignettes of cases from the FANS caseload to demonstrate the various support provided, and interviews with people who have first-hand experience of being supported by the FANS and with staff from other services who have contact with people with dementia and their carers in Flintshire.

The data presented in this report were gathered from various sources, including Steering Group minutes and other FANS documentation. The summary statistics of contact with carers and consultancy tasks were provided by the Admiral Nurse Team Secretary. The vignettes were provided by the Admiral Nurse and qualitative data is provided from interviews with carers and professionals who have worked with the ANS, conducted by a member of DSDC, Wales. These were conducted face-to-face or by telephone or by responses to a brief questionnaire.

Summary statistics of carer contact and consultancy tasks

The criteria for referrals to the Flintshire ANS are:

- The person being cared for should have a diagnosis/probable diagnosis of dementia
- The person with dementia/probable dementia should reside in Flintshire.
- The carer should be agreeable to the Admiral Nurse referral
- Where involvement of a mental health nurse already exists the referrer should discuss the appropriateness of Admiral Nurse involvement prior to referral. (Admiral Nurse Referral Criteria, 2008)

The total number of referrals made to the Flintshire ANS has been 151 from March 2007, when they began to take on cases, until August 2009. Of these, 146 were carers or families, and five were second line referrals, such as other family members. Although the Admiral Nurse model of working allows for long-term involvement throughout the care-giving journey, discharge had proved possible in 94 cases; 65 where the input had been completed, 26 where support from the service had been declined, and 3 which were judged not to be appropriate cases for the ANS. The service closed to new referrals in June 2009, because of uncertainty regarding its future.

Due to the long term nature of dementia, Admiral Nurses use a Case Management Model which reflects the changing needs families may face throughout the journey of the disease. ANs can vary the level of support they offer by means of a case weighting framework, in which there are three categories- intensive input, maintaining, and a holding pool, where input can be rapidly made available if there is a change in the care-giving situation.

In August 2009, there were 39 active cases; 23 with intensive input, 8 receiving maintenance input and 8 in the holding pool. The majority are not open to other services; around 20% of the current active cases involve joint working – with a CPN, Social Worker, Memory Service nurse, or some combination of these; in every case, this reflects the complexity of the case. There was a waiting list of 18 carer/families. The referrers of the carers on the waiting list were contacted to ensure the appropriateness of the case. One carer was thus discharged and it was agreed that input from an Admiral Nurse would be of benefit to the carer/family for the remaining 17. All of the carers on the waiting list had access to or were aware of appropriate services available to them.

Figure 1 shows a breakdown of the sources of referrals to the Flintshire ANS. The highest number of referrals was from psychiatrists and social workers, followed closely by CPNs. These each provided around 20% of the total number of referrals. The wide variety of referral sources shows that the ANS has been accepted by many different services across the county, ranging from the voluntary sector (Alzheimer's Society and NEWCIS), to social services and the NHS (Memory Service, CPNs etc.).

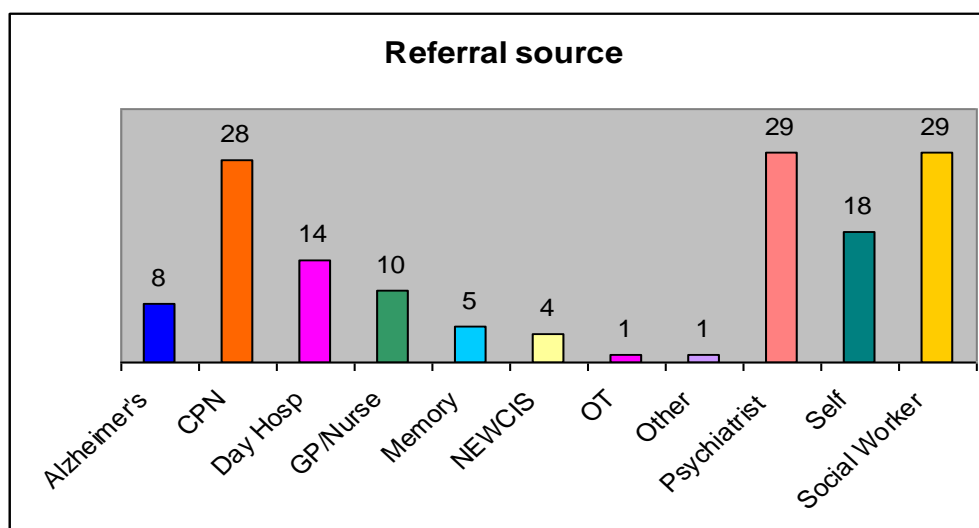


Figure 1. shows a breakdown of sources referring to the Flintshire ANS.

The age and gender of the carers and people with dementia receiving support from the Flintshire ANS are summarised in tables 1a and b. Although the majority of carers and people with dementia were over the age of 65, around 10% of referrals related to a person with dementia under 65 years of age demonstrating the role of FANS in supporting carers of younger people with dementia. The majority of carers were the wife (58) or daughter (45) of the person with dementia, and all but two of the rest were family members (husband, son, sister, daughter-in-law, or niece). The two remaining carers were friends of the person with dementia.

Table 1a. shows the age and gender of the carers, and 1b. of the people with dementia

a.

Age	Male	Female
< 65 years	9	34
>65 years	21	55
DOB unknown	8	24

b.

Age	Male	Female
< 65 years	7	7
>65 years	65	64
DOB unknown	3	5

As stated in the referral criteria, the person with dementia must live in Flintshire. Figure 2 shows the different areas of Flintshire in which the person with dementia resides. The largest proportion of cases relate to people with dementia residing in Deeside, which is where the Admiral Nurses are based.

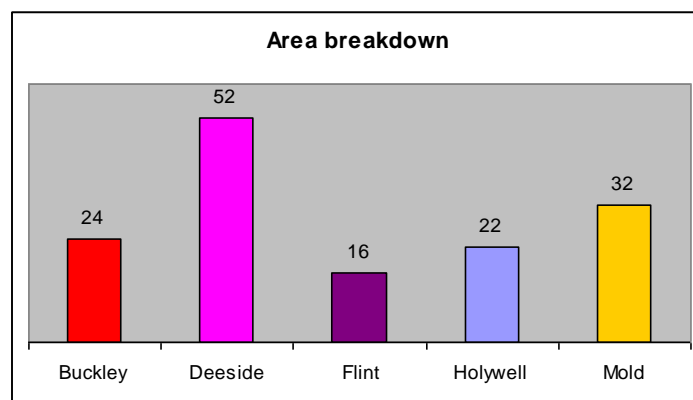


Figure 2 shows a breakdown of areas of Flintshire in which the people with dementia whose carer receives support from the ANS reside.

As well as joint working in complex cases, referred to above, the FANS referred 87 carers or families to other services including the Alzheimer's Society, NEWCIS (North East Wales Carer Information Service), Social Services, and occupational therapists. This is 58% of the total number of referrals to the ANS who have been signposted to other services in the county.

Table 2 shows a breakdown of the contacts provided by the AN team. It shows the different types of contact as well as with whom the contact was made. The largest proportion of contact was liaison work, where the AN liaised with other professionals/services on behalf of the carer/family. This accounted for 47% of the total contact. From this table, it can also be seen that contact with the person with dementia takes up only 12% of contact time reinforcing the notion that the AN works primarily with the carer, where there are nearly four times the number of contacts. Over half of contact was made over the phone.

Table 2 shows the breakdown of the type of contact and with whom for the AN team.

	Carer	PWD	Liaison	Total
Face to face	1513	975	1152	3640
Telephone	2117	70	2721	4908
Written	268	53	626	947
Total	3898	1098	4499	9495

for dementia provide Admiral Nurses with professional development supervision. These sessions were attended almost every month and the FANS went to twenty

five in the period between March 2007 and August 2009. They also attended ten (mainly mandatory) training sessions and eight general meetings, such as the Carers Strategy Group Meeting. In this time period they provided 23 sessions of training or awareness raising, which is classed as supportive education and consultancy activity.

Evaluations for three training sessions given by the ANs were available. Two were "Introduction to Dementia" training sessions and one "Understanding Dementia". Two sessions were for nursing home staff and one was for student nurses. Overall there is feedback from 27 people. All the listed outcomes of the training were ticked by everyone who responded, meaning that there was 100% for each category in each training session. Therefore, all those who received the training thought that the learning objectives were met, that it was pitched at the right level, and that the training was stimulating and interesting throughout. All but 2 of the people receiving training gave feedback and all of the comments were positive. No negative comments were made at all. Among other things, the training was said to be educational and informative, as well as enjoyable and informal.

Carer satisfaction questionnaires

A satisfaction questionnaire (Appendix 1) had been sent to carers who had received a service from the Admiral Nurses in Flintshire. Of 62 forms sent between November 2007 and September 2008, 22 were returned, giving a response rate of 36%. Carers were given the option to return the form anonymously.

The first part of the questionnaire asked the carer to tick one or more boxes to indicate the way that they had received help from the ANS. The most frequent assistance was general support and/ or counselling, although all the listed ways were quite frequently indicated. Figure 3 shows the percentage of responses for each category in this question.

All but one of the carers (91%) who responded rated the service as excellent, with the one other person rating the service as satisfactory. 91% also said they would definitely recommend the service to somebody else caring for a person with dementia, with the one other person saying that they would probably recommend the ANS.

There were three qualitative questions on the questionnaire: 'If the Admiral Nurse did anything above and beyond that listed, please tell us what; Please tell us about anything that you have found particularly helpful; Please tell us if there is anything that you think would improve the service offered to you.' A list of all the comments can be found in Appendix 2.

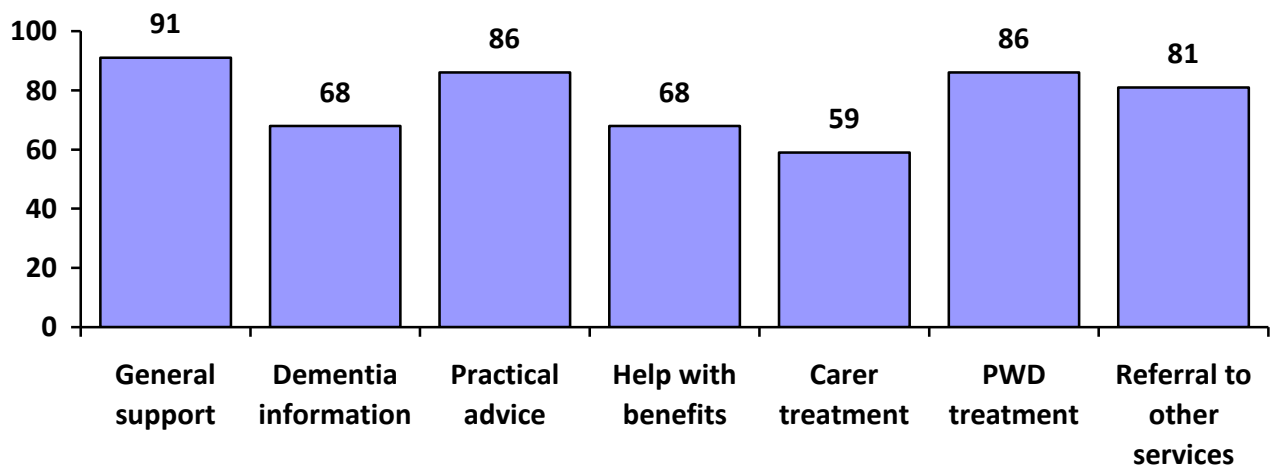


Figure 3. shows the percentage of carers who received help for each category on the Carer's Satisfaction Questionnaire.

All of the comments made were very positive. There were 18 comments about duties provided above and beyond. They speak mainly about the practical and emotional support provided, as well as the constant availability of the AN. The following quote summarises the general feelings well:

"AN is most caring and supportive. We know that we can reach her at any time."

Seventeen carers made comments about what they found particularly helpful about the ANS. Again there were comments about the Admiral Nurses aiding with practical issues, as well as having support at the end of a phone, if needed. The carers also found it helpful to have the AN liaising with other professionals, such as a GP.

"She is a true professional. She goes about her duties with such dedication, offering structural and encouraging advice to myself and my family. She acts as a liaison between myself and other healthcare professionals to ensure my wife and I are receiving the appropriate medication and that all our healthcare needs are met."

There were six comments from carers on ways to improve the Flintshire ANS. The general feeling was that the service could not be improved as it was already to a high standard. Four of the comments include the word "faultless" or "excellent". One person suggests more nurses and another suggests meeting with other people in similar circumstances. The comment below summarises the comments:

"You cannot improve on excellence."

Vignettes of three cases from the Flintshire ANS

The current AN was invited to provide these vignettes to display examples of the kind of support the Flintshire ANS provides. They illustrate the range of work with carers, from education, practical support in filling out forms, and psychological interventions. They demonstrate the complex needs of carers which prove difficult for other services to attend to, often due to the lack of time available for other services to spend on each case. They also show how crises may be avoided by supporting the carer which in turn eases the pressure on the relationship between the carer and the person they care for.

Vignette 1

Carer referred by Social Worker to the Admiral Nurses. The carer was said to lack insight, be impatient, and stressed caring for his wife who had been diagnosed by GTDH (day hospital) to have Alzheimer's. The person with dementia also lacks insight, thinks she still cooks and cleans and sees to her own personal hygiene where in fact her short term memory is very poor and she is unable to remember to take her medication, does not clean cook or wash herself, has occasional episodes of incontinence of faeces and stress incontinence of urine. She has a diagnosis of Chronic Obstructive Pulmonary Disease (COPD) and needs to take her medication regularly. Her husband was very stressed and regularly called her names saying she was dirty, awkward and a liar. The initial assessment by the Social Worker indicated home care would be of benefit to both parties. Both are in receipt of attendance allowance etc. The husband would not engage home care. Admiral Nurse worked with GTDH and Social Worker in supporting and educating the carer which took 6 months before the carer would accept home care. Once home care started the majority of problems were resolved; the PWD's personal hygiene improved and generally their relationship improved.

Vignette 2

The carer was referred to the Admiral Nurses by her GP, she cared for her husband who had been diagnosed with vascular dementia some twelve years ago. The carer lives with her husband with no family members living nearby. She has been the main carer for her husband for over twelve years and has no help/support i.e. home care day care or respite care which she was desperately in need of. There had been six referrals previously to social services on the

carer's behalf each one ended in her saying "no she could manage" and dismissing them. It was apparent the carer was fed up of assessments and the like and this was the reason why she dismissed services. The Admiral Nurse worked with the carer giving advice and support and gaining information so that the Admiral Nurse could fill in the assessment when required on the carer's behalf, and after Admiral Nurse input of just a matter of weeks successful contact was made with social services and the carer now enjoys the benefits of regular respite and day care for her husband, which has proved to be very successful. Admiral Nurse continues to liaise with Social Worker, Day Centre, GP and others on the carer's behalf and has maintained a very good rapport with the carer.

Vignette 3

Self Referral. The son of the PWD referred himself to the Flintshire Admiral Nurses for Anxiety Management following a conversation with his father's CPN.

The carer had experienced a difficult relationship with his father who was a very dominant extrovert man. The PWD had a CPN, Social Worker and was open to the Memory Service. The carer recognised that his caring role caused him great distress and anxiety due to his father's difficult behaviour. Much of the CPN, Social Worker and others' time had been taken up with distressing calls from the father and son.

The Anxiety Management sessions delivered by the Admiral Nurse worked with good effect. Regular follow on sessions have been held to improve and maintain the carer's skills managing his level of Anxiety and improving his relaxation techniques. Carer review meetings prior to Anxiety Management resulted in the father and son almost coming to blows in stand up rows, which caused problems accessing and utilising services. At one time the father was deemed vulnerable, when it was discovered that he had gambled large amounts of money on various schemes. The police were involved.

All involved have worked very well together for the past 2 years resulting in the PWD accepting Home Care, Day Care, and Respite periods. Power of Attorney is in situ and the relationship between father and son being better than it has ever been.

The carer will discuss issues with the Admiral Nurse, these will be signposted to most appropriate department which reduces time involved for Social Worker and CPN.

Carer interviews

Seven carers were interviewed individually as part of this evaluation. A list of eight carers who had agreed to be contacted was provided by the ANS. One carer never answered the initial phone call, nor responded to a message left. The interviewer phoned the carers to arrange a meeting wherever the carer felt most comfortable. Six of the carers wished to be seen in their own home, and one asked to have the meeting in Aston House, where the ANS is based. It was explained to the carers that their participation was voluntary and that all comments would be anonymous but may appear in the final report. The interviews were recorded on a digital voice tracer for the interviewer to use as an aide memoire. Time and resources did not allow full transcription. The carer signed a consent form if they were happy to continue.

Interview duration varied; the shortest was 11 minutes, and the longest 1 hour. All but one interview was carried out with the carer alone; one couple did the interview together. The interviewer had an interview guide consisting of eight main questions:

- How did you first hear about the ANS/ how were you first put in touch with the ANS?
- Can you give me an example of how the Admiral Nurse has helped you?
- Are there any other services involved in the care of your relative i.e. CPN, social worker? Do you know the role of each one? Do you know who to contact for different things?
- How much time does the Admiral Nurse spend with the person you care for? Are you happy with this or do you feel they should spend more or less time?
- How satisfied are you with the Admiral Nurse Service?
- Do you feel they could offer any other services?
- Is there anything you would change about the Admiral Nurse Service?
- Do you have any other comments about the Admiral Service?

Four out of the seven carers interviewed were referred to the ANS by social workers, and the remaining three by a memory clinic.

Examples of how the ANS has supported the carers varied in all the cases- practical support in filling out forms, educating the carer, practical advice in how to deal with the person with dementia day to day, coping strategies, liaising with professionals.

“She is very good. She knows her job and any queries or problems we have...she does sort them out and she liaises with Dr. [family GP], our doctor, if she has a query.” Carer 1

“But she knows, she’s an intelligent lady, and I know lots of carers wouldn’t want to know the ins and outs but I do. And she tells me what to look for, what mood swings, how gradually over the years he’s changed, nobody else has told me, well I’ve seen it for myself obviously but she explains and goes through it with me and I find that very helpful.” Carer 2

“She’s always telling me what to do, like if [husband] gets a bit uppity, you know, agitated, just walk out and back in five minutes you know, and it’s true he doesn’t remember and it’s all gone so it’s good advice. She’s always giving me advice you know.” Carer 3

“I was terribly, terribly depressed so she said ‘get a hobby, something to take your mind off things. Do you knit?’ I said yes so she took me to Abakhan [fabric shop] to buy wool to knit coats and bonnets for the premature babies unit. So I did and when I finished them, there were 4 sets, she took them for me to the place and they were thrilled with them.

It [knitting] took my mind off things. I used to sit here at night but while I was knitting it stopped me worrying so much.” Carer 4

“Whereas we’ve been able to mention things to the Admiral Nurses and they’ve been able to smooth things out. Because it seems to be when you go to professional people and say you know mum doesn’t know she’s got this, they want to take on the role of telling her. Whereas she’s [AN] been able to go in and she’s been able to explain that it has been decided professionally that this is the way forward for my mum. It’s made things a lot easier that way.” Carer 5

“She’s helped us hugely with Social Services ‘cause I had to give my job up to look after mum and dad and we didn’t know anything about benefits and I’ve been able to go as a full time carer now which we wouldn’t have known and mum and dad wouldn’t have had the help they needed.” Carer 5

When it came to knowing the role of the AN compared to other services, the reactions were different. In the cases where the AN saw the couple together, the role of AN did not appear to be known as clearly as when the AN saw the carer alone. In one case, there were no other services involved.

“Shall I tell you how I see it? My social worker.....she is absolutely brilliant..... The way I look at it is, the CPNs are for [husband]. If [husband] has a problem, I ring them. That’s my first port of call if I can’t deal with. But for me, if I have a problem that I can’t deal with, then I ring [the AN].” Carer 2

“I think they work together as a team as far as I know, in Aston House.” Carer 3

“[She’s] an Admiral Nurse, isn’t she and she’s there for me really, to help me. [CPN] is more for mum ‘cause she’s a CPN but she’ll come here when mum is here.” Carer 6

When asked how much time the AN spent with the person with dementia, again there was a divide in the answers. Although all were happy with the balance that they received, there were two different situations represented. There were 4 carers who saw the AN together with the person with dementia, although one carer also arranged to meet her separately at times as well, and 3 of the carers saw the AN on their own, usually when the person they are caring for is in respite or day services. Another theme that emerged from this question was that the role of the AN differed if she was the only regular service involved; e.g. she took blood pressure of both carers and people with dementia.

"We look forward to seeing her and we enjoy her being with us and we know that she will help us if we have a need for it." Carer 1

"It's invaluable because she comes every month and she takes both my husband's and my blood pressure. And she talks to [husband] which is a help.

If she want's me to go out of the room, she'll say." Carer 3

"It's difficult to take mum out. She doesn't want to go out anywhere and when she does go out she can say inappropriate things. Having [AN] come out... she's been doing blood pressure and stuff, stuff that Mum needs but we find it difficult to take her." Carer 5

"No if she's going to see other people in the area [of the residential home], she'll drop me off and pick me up but she'll go in to speak to him [husband] and say hello....but when she calls, it's to see if I'm alright and if there's anything I want her to do. She's very good." Carer 4

"She used to come mostly on the days when mum was in respite really because she would say it is you I'm coming to see.....

Some days when [AN] can't make it on the days mum's at respite, she'll come here while mum's here but [AN] is more for me, type of thing." Carer 6

"I haven't been very well myself. I suffer from bad blood pressure. It goes up and down like a yo-yo and sheshe always takes our blood pressure when she comes...." Carer 7

All of the carers were overtly satisfied with the service provided by the ANS, and none could suggest any other services they felt the ANS could offer.

"Their service is excellent" Carer 1

"110%!" Carer 2

"More than satisfied!" Carer 3

"Very satisfied!" Carer 4

“Hugely [satisfied].....Anything that we’ve asked for she has tried her best to fulfil anything really, if she can’t do it herself then she can put us in touch with somebody who can help. She seems to have most of the answers and if she doesn’t have the answers she knows somebody that can get them.” Carer 5

“Fantastic. Can’t fault her. I really can’t fault her. 100 out of 100 I tell you. She’s brilliant!” Carer 6

“Very satisfied, very satisfied. As I say, I’ve only ever met one but if they are all like her then they are all good.” Carer 7

None of the carers would change anything about the service provided, other than to continue it. The general feeling was that they were already going the extra mile.

“Well what I would change is the fact that they have a secure job and that they be there for me for as long as I need them, that’s what I’d change.” Carer 2

“I think she does above and beyond the call of what she is supposed to do I’m sure she does” Carer 2

“I mean what could you change? They go out of their way, no there isn’t anything to change. You couldn’t ask them to be any better than they are now.” Carer 3

“Not really ‘cause she does everything like, you know that I need really. If I need [AN] she’s there for me. There’s nothing I can say. There’s nothing bad about her.” Carer 6

“No, she does everything she can.” Carer 7

When asked to give any other comments about the Flintshire Admiral Nurse Service, the carers were all very positive.

“To me she’s worth her weight in gold...quote me!” Carer 1

“I don’t think I could say anything else really could I?! It’s just been a huge support for the whole family. It’s given me an understanding of the condition, you know, and that’s something you don’t get from consultants because they just don’t have the time.. And it’s a spin off from there. They can tell [AN] what’s going on and she can bring it back to us and explain it to us in terms we understand.” Carer 5

“I think the guy who thought it up was spot on.....I had heard of them funnily enough on telly or whatever, but I hadn’t really delved into it and I didn’t realise until I had [AN] how important they are.” Carer 2

“I think they are excellent to be honest with you. They are excellent, you know, and very very kind.” Carer 4

“Only that I praise them for all they do. If they are all like her, as I say, you know....I can ring her if I’ve got a problem, or if I didn’t feel well I could ring her and tell her and she’d come up and see if I was alright...if she hasn’t got another appointment, like. She’s very good, she really is.” Carer 7

A theme that emerged in the interviews was the worry for the future and whether the service would continue. There was also the feeling that the carer would be lost without the support from ANS.

“The Admiral Service is excellent and it would be a great shame if it was discontinued” Carer 1

“So many of these things are political. It’s lay people sitting on these committees taking a vote on whether I need an Admiral Nurse. I find that very upsetting. And then after 2 ½ years, to take her away from me is bad.

But I wouldn’t have been able to cope with all these horrible horrible moods swings..... if I hadn’t had [AN] there to go through it with me.” Carer 2

“I hope they keep her. I do honestly, not just for me, for all the patients. As I say, it’s nice to have someone there on the phone.

I hope that they keep her on and get the funding if that’s what they need.” Carer 3

“I think she is doing a wonderful job. Without her I would have been very very depressed. She got me out of it. She’s very kind really.

I hope they keep it on because she’s been good to me and if other women are on their own, you need somebody like that. She’s been excellent with me.....I think, from my experience, I think they are needed. Because I didn’t know what had hit me when [husband] was taken ill so suddenly.

I’d miss her. As I said I don’t see her regular like every week or anything like that but she’s always there if I’m worried or anything, which is good.” Carer 4

“I think it would be a real shame if we lost the service, because you’re out in the cold otherwise.” Carer 5

“I think it’s a brilliant job they are doing. Absolutely brilliant. I just wish there was more of them about.

I don’t know what I would do without [AN] now, I don’t.” Carer 6

Another theme that ran through all of the interviews was that of the personal attributes of the AN.

"I feel at ease with her. She's a friend. She's not high-faluting or way over the top, she's very down to earth; very kind. She's very kind..... In other words we love her.

The service is more personal, without interference, without going over the top...um... say... um... community nurses they look after you but they don't give you the service that [AN] does.

Put down we adore her!" Carer 1

"She's very very kind. She was a godsend to me.

She's a kind person and its not just me that she's like this with, it's with all of them. She'd be kind with anyone." Carer 4

"They need them everywhere. For people, especially carers like me. The first 2 years I was on my own, I didn't realise there were people out there that can help me. And then when you get people like [AN], you're not on your own anymore. You feel like you've got someone you can turn to at last. As a nurse...but as a friend as well, someone you can turn to, really, when you need help." Carer 6

"And she's very pleasant as well you know. She's always smiling and she'll have a joke with my husband, try and get him to talk.....things like that.

She's turned out not just a nurse, but a good friend...someone you can talk to, things like that. If I've got any problems I can talk to her. Yes she's good." Carer 7

Interviewees all agreed that having someone at the end of a phone was very valuable. They all said that the AN got back to them as soon as she could and always on the same day.

"I just know being on my own, a lone carer, with no family, that she's there, she's my comfort. If I pick up the phone, I can talk to her. And that also is so, so wonderful because everybody is busy, busy aren't we but she always finds time for me." Carer 2

"It's just nice that you've got somebody at the end of the phone who you can ring up.

You're not sort of isolated.....Having someone who specialises that's on the end of a phone whenever makes a huge difference. The pressure you're under when you've got somebody with this condition is unbelievable really." Carer 5

"Once I'd talked to [AN] I felt better. I don't know what it was, as though she's there; like I'm not on my own anymore. 'cause I'd been doing it for 2 years on my own and I couldn't cope anymore." Carer 6

"It's nice to know I've got somebody I can ring that will come and help me if I'm stuck with anything..... I can talk to her and I can ring her and have a little chat, things like that. It's very helpful; it makes me feel better in my self, like." Carer 7

Meetings with members of the Steering Group and AN Team

The main issue brought up from the meeting with members of the steering group was about the balance between consultancy work and direct case work. The discussion document, 'Admiral Nurses in Flintshire', written by the steering group, suggests a balance of 70% consultancy and 30% casework for the Lead Admiral Nurse, and it had been felt that this was not being achieved. The AN team felt that for this to happen, the AN had to take over cases from the Lead AN, leaving less time for her own cases. Now that the Lead AN has left, at the moment the AN spends about 4 days doing case work, and 1 day of consultancy/training each week.

The view was also expressed that the ANs were focusing too much on the person with dementia, rather than on the carer, and were perhaps being too clinical in emphasis. It was suggested that perhaps they should rather be taking on cases referred by CPNs where the carers are struggling. The Admiral Nurse Team, however, felt that they were making a difference for families with complex needs for the CMHT as they have had referrals from them. They also reported that they had been assigned to the person with dementia in referral meetings with the CMHT in some instances.

The Steering Group members discussed initial problems in setting up the service. They felt that there was confusion over who was to lead the Steering Group. It was initially led by the Local Health Board, and then it was assumed that **for dementia** would take over. It was felt that the relationship between **for dementia** and the Steering Group had been difficult at times, perhaps reflecting the difficulties experienced by the ANS in finding its place within the broader service context. The AN Team also discussed initial problems with setting up the service. Their employment by **for dementia** rather than by the Trust (as would typically be the case) was a requirement of the funding body, but led to all manner of practical and logistic issues, not least because of the delay of some months in obtaining honorary contracts from the Trust. The ANS had to buy their own equipment and even build their own desks! More importantly, they also had difficulty in accessing case notes because they were not Trust employees – a situation which should have been resolved with honorary contracts, but which continued to lead to difficulties at times. The team felt it was difficult for them to be accepted, perhaps because there was an element of fear of the unknown, and it appeared that there was much uncertainty regarding their role on all sides.

Interviews with professionals

The interview guide for the professionals consisted of the following questions, developed to explore the issues raised by the steering group:

- How much involvement have you had with the Flintshire Admiral Nurse Service?
- Have you made any referrals to the ANS?

- If so, has it eased your caseload?
- Have you had anyone referred to you by the ANS? If so, have you had any feedback from the families?
- Do you feel that it is an advantage that the AN is a nurse? Could you see a similar service in a social services setting? Should it be more integrated into the CMHT?
- How satisfied are you with the ANS?
- Please comment on the extent to which the ANS works with both carer and person with dementia - is the balance about right?
- Please comment on the extent to which the ANS works through consultancy rather than direct case-work – is the balance about right?
- Is there anything you would change about the ANS?
- Any other comments?

After initial meetings with two members of the steering group and another with the Admiral Nurse Team, contact details were provided of professionals who have worked alongside, referred to, or had referrals from the ANS. They were contacted by phone to arrange a meeting with the interviewer. Where the interview was recorded, interview duration ranged from 12 minutes to 38 minutes. Three of the meetings could not be recorded but notes were made by the interviewer. One professional was unable to arrange a meeting so answered the questions via email. A shortened questionnaire with 5 questions was sent via email to NEWCIS staff who filled it in together as a team.

All of the professionals that were interviewed had made referrals to the ANS, and some have also joint worked with the AN. The general feeling was that having an AN involved in cases, eased the workload on the case. However, most commented that they hadn't made many referrals recently because of the uncertainty over the future of the service.

"It has certainly eased the pressure and the amount of phone calls we get from families in crisis and stressed out.

*To be honest I've got somebody that I would like to refer but I'm holding back 'cause with the funding not being known, whether the service is going to be available and I know that [AN] is not able to take anyone."*S/W

" When working with one particular AN, I found joint working beneficial, I would not say that it eased my case load, but it was good practise and made good impact for the carers"
Member of CMHTE

All had heard feedback from families, mostly positive. A senior practitioner reported excellent feedback from all the families she had spoken to. A consultant psychiatrist said feedback they had received from families was that the availability of the AN, and the provision of practical advice were positive aspects of the service. This is supported by feedback given to a member of the memory service.

"I think the positives were there was a good point of contact for carers and they felt that they were able to ring at anytime and they had that response at any time, from a carer point of view." Memory service

".... the feedback I've had from them is very good, from the carers." GTDH

"Yes certainly, I'm still seeing the gentleman that I'm dealing with is still open to me and I speak to his son on a regular basis, and he says he's benefited...he's derived benefit from [AN]'s input and ongoing input there really and I think he'd probably feel a little bit at a loss really, you know if and when the post goes off." CPN

"It's always been extremely helpful and they've kind of liked them - you know - maybe because it's very informative." Senior practitioner

"The support is welcomed and very much appreciated by carers and their families." NEWCIS

"...the positives were that the carers felt supported, that there was support for them." Member of CMHTE.

There were also a few negative comments made by families to the memory service:

"Also we had some negative points of view which could have been our own making really and that's they kind of made problems for the carers rather than...but this is only a couple of families mind...where the ANS went in and then looked at the carer and perhaps labelled – not labelled the carer, but made the carer more aware of their own health needs, which perhaps became more problematic in the long run. I don't know, it's only a judgment isn't it? But that certainly happened in a couple of families. It's difficult really, but then that was when they were just starting off so... on reflection now that we haven't got an ANS, you can always highlight people the service would have been useful for in those instances." Memory Service

This was also mentioned by a consultant psychiatrist. He thought that it was only two families who made complaints to CPNs but didn't think that these were ever formalised or followed up. (We have been informed by **for dementia** that no complaints have ever been received by them about the FANS from carers or others).

"It was more in general, like the family I referred everything went wrong, but whether it would have gone wrong anyway, who knows? It's difficult families in fairness. Other than

that, I think it was more the intensity maybe that they've gone in, they've seen the carer, they've done so much with the carer, which is good as that's their role, but perhaps they haven't been sensitive to the whole rather than...which is hard isn't it. And carers perhaps don't want to be perceived as carers, you know when they are family members, and what have you. But it works in some cases and doesn't in others. But that's the same for most things really." Memory Service

"The negatives were around the actions/comments by one particular member of the ANS who at times did not listen to the needs of the carers." Member of CMHTE

Most professionals felt that it was an advantage that the AN is a nurse. Professionals felt that someone from a social service background would not have the in-depth knowledge of dementia to be as effective as the current AN. A consultant psychiatrist felt that it didn't matter whether the support came from someone with a health background or a social background, just that carers need support. The member from the memory service was unsure as they could see both sides to the argument. However, they were in the minority and the general consensus was that the AN should have a nursing background.

"Personally I feel that a nurse is... with background knowledge of things like Alzheimer's is best place I have to say really." CPN

"I think it is important that they are a nurse. I think it's important that it's a psychiatric nurse because obviously they have much more insight. I think social services are limited to what they understand really. That's my personal opinion...we work with social workers and they'll come up to us and say you know, 'Have they got dementia? Have they got Alzheimer's? You know, it's all the same thing isn't it' you know what I mean and it's really difficult because you think well you're supposed to be working with these people, surely you should know. I'm sure if somebody's...well up to date with things, I'm sure, you know...I would prefer a nurse in the position myself." GTDH

"... I think a nurse looks too much at health and medicalises things when perhaps they don't need to be medicalised and perhaps that's a disadvantage of it being a nurse. But then being a nurse, you've got that background knowledge as well and you could perhaps, but I suppose it depends on what role you've had previously really. I don't think it would have to be a nurse."Memory service

"I think it is yeah [a benefit] that it's a nurse rather than a lay person. To me I think it should be a nurse, you know" Senior practitioner

"I think you've got the CPN skills there that you can actually discuss with the families the disease or the symptoms and cause and effect almost. They can tell them what to anticipate as well, what could happen, what to expect. They've got a more of an in depth knowledge of the conditions that they are dealing with really...which I think we've learnt from as well

because the carers seem to talk about what the AN has talked about and it's something we take on board as well." S/W

"Don't feel social services currently have the skills re: knowledge of the illness..." Member of CMHTE

Most of the professionals thought that the ANS should be integrated, or at least work parallel to the CMHTE.

"I'm not sure whether it needs to be exactly in...well certainly from my point of view it worked quite well that [AN] has been employed by another body and...from a practical point of view I think it has worked quite well the way it has been. [AN] has been in the building I suppose." CPN

"I felt their role was integrated really, certainly initially they were part of the team. I mean that could have been improved on...I don't know, I think maybe because we shared an office we kind of, you know if they were on the phone with someone, you'd think 'God I'm involved with them as well' so it was more networking but I think perhaps the role could have been networked better really but then I suppose it's the best use of their time as well isn't it because it wouldn't just be the CMHT, it would be social services as well wouldn't it. I don't know... but I think it could be improved on really. I felt that to begin with they were more part of the CMHT because they used to come to the referral meetings and what have you, but then I think that stopped or I think they used to come monthly.

I think in fairness to the ANs, there were a lot of barriers for them to jump over when they started and it must have been quite difficult for them to set up the service, as it is in any new service. People do put barriers up don't they." Memory Service

"What ever is set up/offered should be integrated in the CMHTE" Member of CMHTE

Most of the professionals interviewed said that they were satisfied with the Flintshire ANS. A consultant psychiatrist expressed satisfaction with the service and has great admiration for it as the ANS have dealt with some very difficult cases.

"With the current service, I have to go back to [AN] now as I've been dealing with her, I've been more than satisfied really, I think we've worked well together." CPN

"It is a good service and I think it is needed. And we'd very much like one in Denbighshire!"GTDH

"At present? At present, yeah, very satisfied." Memory service

"I think it's invaluable, not just to carers but to us, as a service. Just takes the edge sometimes. We often have screening taking carers on, what can we do, where can we go...and NEWCIS they don't offer emotional support, they only offer that practical support there's occasions that they have emotional support where they have groups, but that's not

for everyone is it? And I think sometimes people need to have dementia and Alzheimer's explained to them because they don't understand it and they are trying to deal with it on a day-to-day basis and it's just somebody individual for them to sort of feed of and discuss things with. They are professional and seem to know the impact of dementia because that is the group of people that they are dealing with on a regular basis whereas our client group is very very mixed." S/W

"Very satisfied" NEWCIS

"The ... AN who worked with the carers and kept good lines of communication with the relevant professionals provided the service we felt was needed." Member of CMHTE

There was however a comment that early on one AN was seen as having stepped over the boundary of working with the person with dementia without consulting with others involved in the case and for one CMHTE nurse this had *"led to a number of confrontations which damaged relationships beyond repair"*. These initial problems seemed to have coloured views of the whole service.

A consultant psychiatrist commented that the CMHT appeared to think that the ANS would work exclusively with carers and not be involved with the person with dementia, but suggested that this was unrealistic as when seeing a carer, the nurse will naturally be concerned about the person with dementia; a view echoed by GTDH and the senior practitioner. A CPN commented that the good working relationship between the CPN and AN means that both are aware of their roles.

"It's quite difficult, I think there can be potential conflicts about boundaries and I think you have to have a really good working relationship to sort of say 'ooo are we encroaching on one another's territories?' really.

She would make it very clear and would say 'oo' when he'd say 'what should I do about Dad?' and she'd say 'oo, that's not really my job. I can give you some advice but really you need to speak to [CPN]' and she was very clear and she would always come back and say "[CPN], he's said 'oh dad's doing this, this and that', and I've told him that's your job" and [AN]'s always been very sort of careful....and I think we have been aware of our roles and anxious not to...come into any conflict I suppose." CPN

"Well my view was that they were specifically with the carer, however I do know that the client is obviously their concern and when I have spoken to [AN] several times I found that they were both her clients, if you like, not just the one. You can't just ignore the one because it's a knock on effect to the other isn't it. When I've spoken to [AN], it's been them, not just the one." GTDH

"Some of the cases that I've been aware of, I think it has perhaps been right and in other cases perhaps not. But then you wonder if there are too many people involved in the case, 'cause if you've got social services, CPN, ANs that could be quite confusing for the people

involved as well, especially as you are all singing from the same hymn sheet really, so I think from the service users' point of view it could be a bit daunting. But then long term because inevitably people have to pull out because of case work, how ANs manage their caseload is perhaps a bit better because they have that pool don't they, where people can dip in and dip out so I think it's something that could be improved on really. I think it's about being aware of your roles isn't it and saying well if you're going, sort of stepping back and being confident of their role as well." Memory service

"I think it's more rounded than just seeing the carer, because they are kind of giving advice on stuff that will make it easier for the carer, but they've got to look at the service users as well haven't they." Senior practitioner

"In fairness, I think [AN] has been very good at just working with the family member rather than the person with dementia, that is somebody else's role and I think [AN]'s let people get on with that and she's not overstepped the mark. [AN]'s role is for the family.

Even so, when I've had two people who've been at loggerheads constantly because the wife tells the husband I want you to do this, I want you to do that, she's taught them strategies like laying his clothes out so he recognises when his clothes are out, he goes for a shower, so it's diffused a potential situation there. So although she doesn't get completely involved with the cared for, she is...helping to diffuse situations which could go off, because they do go off like bottles of pop, and because she's feeding back to us, we can deal with the service user issues rather than [AN] getting involved in that, she hasn't needed to as she's shared the information with us so we would do whatever we need to do, or the CPN or whatever." S/W

As discussed previously, one member of the CMHTE thought that one AN had overstepped her role and created some confusion:

"As mentioned before, the organisation was presented to us as a service for carers, so it created a service within a service which did create some confusion for all. It would have been better had they concentrated purely on the carers."

Only the senior practitioner and the social worker could comment on the balance between consultancy work and case work, most other professionals interviewed said that they didn't know much about that side of the service.

"I would have thought it was too small of a group of them, you know only two of them to be able to...[provide training]." SP

"I'd prefer her to do the case work actually as I say it takes a weight of our shoulders. We've got other agencies like the Dementia Living Well Project, you know they are projecting courses into the county and we have quite a lot of training on things like that. As I say, we learn from the AN as well but it's more of a hands on approach rather than a classroom."
S/W

Suggested changes to the service mainly focussed on paperwork and sharing of information between services. The other change commonly mentioned is to have more ANs.

“Probably their note-keeping because I have to struggle when...if we’re joint working with someone, we’ve got separate case notes. I don’t think that’s practical... I mean we’re at an advantage I felt ‘cause we share an office, so I could just say to [AN], ‘well I’ve got the case notes here’, and things like risk assessments, I don’t think we share that enough so I think those are things that we should have improved on. But it’s that sort of general...and the assessments really, they do that burden stress scale, and we do a rating scale and it’s sort of sharing of information, I think that could have been improved on really so that we’re not both doing the same job really. But definitely sharing the case notes. Especially when they are joint working with someone that’s on your caseload, I think you should have a knowledge of what they are doing with the carer, and planning visits, you know even if you did joint visits to begin with, I don’t know I think that could be improved on really.” Memory service

“There doesn’t seem to be anything [changes to be made to ANS]. It seems to be a well thought up scheme, you know, well planned and they seemed to know what they were doing. Although that might be me because although I didn’t know the other lady, I’ve known [AN] for a long time so I felt very comfortable, you know, that she knows her stuff so there was no problem really, which was quite nice in terms of having somebody to set up a scheme in the area.” Senior practitioner

“We need more of them. Because it really did impact us when [AN Lead] left because as I’ve said we’re holding on to referrals because we’re unsure whether it’s going to be there. And you know that the family are going to be struggling and they just need somebody extra to support them through some of it.

We want 5 please!

I think [AN] could do the carers assessment <laughs> no, because they don’t have any paperwork, I think that would be an improvement if we could get more of a background about the carers themselves, which possibly would help for our unified assessment.” S/W

“Employ more nurses and extend the service across North Wales” NEWCIS.

Emerging themes from interviews with professionals:

Initial problems: Some of the professionals interviewed spoke about initial problems for the ANS. They were unsure of the role of the AN and whether they could refer carers when other services were involved in the care of the person with dementia. Most felt that these initial problems were resolved though.

“Initially, we found it difficult as we didn’t really know whether to refer to a CPN or the AN as we were unsure of the role of the ANS.

It’s really difficult because, that’s another question because, it was again, do we refer for an AN or do we refer for a CPN. We were unsure if they had a CPN whether they were allowed an AN. But I think AN should be part of the Trust. That they shouldn’t be independent as it puts barriers up straight away I think so. I think maybe they should be part of the Trust, working as part of the community psychiatric team. It just brings those hurdles down.

Like I say, initially, the first sort of 12 months was sort of teething, you know, how do we refer, what is the protocol, what’s the criteria? But once it was established it was easy, you know.” GTDH

“I think in fairness to the ANs, there were a lot of barriers for them to jump over when they started and it must have been quite difficult for them to set up the service, as it is in any new service. People do put barriers up don’t they.” Memory service

Evidence of need: The statements below sum up the feelings of the professionals interviewed as to the need of an ANS in Flintshire.

“CPNs are constantly needing to move on to the next person so they are limited the amount of time they can actually support somebody, whereas the AN, they are there. Yes they may need to support somebody heavily for a certain period of time and then they may be accessed later on, mightn’t they...You know, and that’s the kind of service that I think the carers need, definitely. Especially as the dementia progresses as well, you know, and people are living longer. We’re just sorry we haven’t got any this end!” GTDH

“And that’s something we don’t provide, and the Alzheimer’s Society don’t provide, and it’s sort of end of life. ‘cause we were saying, like we’re obviously involved with people right the way through their journey with dementia and then if they come off medication, say the memory meds aren’t beneficial, then we kind of step back, and I’m thinking they’ve had all that input, say 5 years and we step back. But the ANS wouldn’t would they they’d keep going and I think sometimes that’s missed. “ Memory service

“I think you could evidence how they were needed probably by the amount of referrals they got, ‘cause I think they were overwhelmed weren’t they by the amount that came through.” SP

“It’s a service greatly needed” S/W

Most of the professionals spoke about the uncertainty of future.

“I just think it’s such a good development and especially the media, they’re linking to it, it’s getting all that coverage, loads of advantages to it and I just find it so frustrating that they

are in the state they are and the predicament for the girl that's left there now, I think it's disgusting."

"But I think, especially as they were the first ANS in Wales, it's such an achievement and it's all gone down the pan. I find it very frustrating. Especially for the development of dementia services in general and sort of identifying people's needs and showing that it's not an easy job looking after somebody with dementia. So I think we should have an ANS."

"The whole system has kind of been geared towards their expectation that the Admiral Nurse would be an on going thing so it's come as a bit of a blow to them [carers]."

"And of course the people in the community they probably don't quite understand what's going on. I don't think it was made clear that it was just a trial was it?"

"If the service were to stop it would impact on our role because our turnover wouldn't be quite so quick because we'd be dealing more with the carers rather than the cared for themselves. We need somebody to focus on the carers. We've had the champion taken away from us..."

Some professionals mentioned how much they appreciated the fact they were given regular feedback from the AN. This was done usually over the phone.

"You get regular feedback from her as well. You don't have to say oh I wonder if [AN]'s going to call us. She always calls us to give an update."S/W

"And referrals were picked up, you know, if we do refer, referrals were picked up and fed back as well, [AN] always fed back what was happening, which was really good as it kept us in touch with her." GTDH

Conclusion

The evaluation clearly indicates that the Admiral Nurse Service has become a valued component of services for people with dementia and their families in Flintshire. If it closes, it will be missed by carers and professionals, some of whom sensed that an opportunity will have been missed to build on the learning from this project in developing similar services across other parts of Wales.

Speaking to the professionals provided a clear case for the need for the Flintshire ANS. When looking through the caseload, the senior practitioner identified nine families that she would refer to the ANS. A consultant psychiatrist stated the need of a dedicated carer support service for carers of people with dementia as he felt that all existing services were being systematically withdrawn. Examples of these withdrawn services included the Alzheimer's Society Advocate and the Carers'

champion. An email from a member of the Lotus Group, a service user/carer group from North East Wales, was sent to a senior nurse expressing upset at the discontinuation of the service after speaking to a carer who was very distressed (see Appendix 3); and we understand that the service has had a letter of support from Carl Sargeant, AM.

“Good Health, Good Care. Flintshire’s Strategy for Improving Health, Social Care and Well-being 2008-2011” declares both carers and older people with a mental health problem as a priority. It is stated that carers should have “access to a range of flexible, imaginative and responsive support, including in times of crisis” (p.58). This flexible approach is embodied in the case management model of the Admiral Nurse Service meaning that levels of support can be varied. Later in the document, it is stated that an outcome to be aimed for is that more people with mental health problems, such as dementia, should remain in their home and the community for as long as possible and that their carers should have the appropriate support. This again is something that can be achieved by providing support from the Admiral Nurses. Indeed, the strategy gives a performance indicator of an “increase in number of carers supported by Admiral Nurses” (p.64) and sets a target of 160 families over 3 years.

A number of sources reflected the teething problems in the early days of the service and the difficulties apparently emanating from the team being employed by, and receiving supervision from, an external agency, leading for example to practical issues with furniture and organisational issues regarding the relationship with the CMHTE and access to case-notes. From some comments made by professionals, there were clearly tensions and some conflicts between the AN Lead and other professionals. It is not within the scope of this evaluation to conduct an inquiry into these difficulties. The key points arising are that these issues clearly coloured views of the service in its formative stages; that the service has now moved on and achieved a collaborative approach with the whole range of other agencies; that although this particular situation may not have been foreseeable, there is broad agreement that other aspects of the establishment of the service could have been achieved more collaboratively. From experience elsewhere in the UK in relation to the establishment of Admiral Nurse Services, this clearly reflects a particularly unfortunate one-off situation, rather than being a systemic feature of Admiral Nurse Services.

Overall, the evaluation of the service as it has now developed has been overwhelmingly positive. Carer and professional viewpoints are in broad agreement. Although it could be argued that any service to support carers would receive a similarly glowing evaluation, there is ample evidence that the specific attributes of an Admiral Nursing service, including the professional knowledge and skills of the AN, the commitment to availability throughout the care-giving journey and the explicit inclusive focus on the carer are recognised by and valued by the range of stakeholders.

A number of key issues were addressed with stakeholders in order to inform potential ways forward, and each of these will now be addressed in turn:

How important is it that the service is provided by a nurse? The view here was that the knowledge and skills were the key factor here, and that, by and large, mental health nurses with experience in dementia care, were more likely to be well-equipped to take on this role, and to take a holistic approach to health and well-being. They also have the skills to deliver psychosocial interventions for the carer, which fits well with NICE-SCIE guidelines on dementia care (2006) and draft WAG targets for the NHS on dementia.

Where is the service best located organisationally? In Social Services, NHS or third sector? The need for close working with the CMHTE came through strongly, and although, in principle, the service could be located in any of these sectors, on balance the NHS appears the most appropriate, especially if the service is provided by nurses.

To what extent should the Admiral Nurse work with the person with dementia, if the carer is the primary focus? This has clearly been a contentious issue at times. The Admiral Nurse model emphasises influencing the whole care-giving situation, including the all-important relationship with the person with dementia, by primarily working through the carer. This cannot be achieved by being 'blind' to the needs of the person with dementia. The evidence available clearly indicates that the FANS has had a focus on carers, with nearly four times as much contact with carers as with people with dementia, but there is also clearly the flexibility to have direct contact with the person with dementia where this is required and agreed with other professionals involved. In the majority of cases, involvement of the Admiral Nurse alone is sufficient to address the needs of both carer and person with dementia, which are met primarily through working with the carer.

How best should Admiral Nurses work with CPNs? Again the evidence suggests that a way of working, satisfactory to all, has evolved where the AN provides on-going input to the carer, and the CPNs involvement is called for as necessary. In the majority of cases, CPN involvement over an extended period is not needed, and it is only in a proportion of cases (around a fifth) where the situation is so complex that joint working is required. CPNs felt the Admiral Nurse model lent itself well to carers with complex needs, and valued the possibility of longer-term involvement that could be provided. CPNs reported that when working jointly, the current Admiral Nurse was careful to ensure the CPN was involved in issues directly related to the person with dementia.

What should the balance be between case-work and consultancy / training aspects of the Admiral Nurse role? It was surprising to hear that the Steering Group felt that there was insufficient emphasis on the consultancy aspects of the role. Elsewhere, AN services have been pressured to deliver more casework. The credibility for

consultancy arises from a solid base of work with carers and people with dementia, and there needs to be some scope for this aspect to grow organically from the work being undertaken, as service gaps and training needs are identified. The team, when fully staffed, was small and so having a greater emphasis on consultancy inevitably had a dramatic impact on the number of families that could be helped. There was, however, clear evidence that the service has had an impact not just on the carers receiving it, but also on the broader system. Social workers commented on their learning from the Admiral Nurses in the context of cases, and judged this of greater value than emphasising consultancy work.

Definitive answers to these issues, which were initially raised by the steering group, may not be possible, and in some instances there were arguments for and against. However, we conclude that, having worked through some challenging teething difficulties, the current Flintshire project does now provide an excellent launch pad for future working, providing an evidence-based model that has broad support from the range of stakeholders.

Recommendations

It is recommended that the service continue within an NHS context, integrating with the CMHTE, to ensure overlap of cases only where the complexity of the clinical situation necessitates this, allowing good local management arrangements, whilst continuing to benefit from the professional development supervision which **for dementia** offers to all Admiral Nurses. The service would then continue to be carer-focused, but not blind to the needs of the person with dementia, and the Admiral Nurse's role in working with the carer in relation to these needs is a vital aspect of cost-effective evidence-based psychosocial interventions. It would appear from the referral rates and waiting lists that 2 nurses are required to provide this service to Flintshire. It is recommended that rather than setting down specific expectations for the amount of time spent on work other than direct case-work, the range of evidence-based interventions for carers be allowed to develop to include, for example, group interventions, where appropriate and inputs to the development of related services. This balance may be revisited if and when there is investment in expanding Admiral Nurse services to provide input across a broader geographical area in North Wales.

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Admiral Nurses in Flintshire. Discussion document., 2008

Admiral Nurse Referral Criteria, 2008

Flintshire Admiral Nursing Operational Policy., 2007

Good Health, Good Care. Flintshire's Strategy for Improving Health, Social Care and Well-being 2008-2011.

Appendix 1: Carer satisfaction survey sent out to families receiving support from Flintshire Admiral Nurse Service between November 2007 and September 2008.



I understand from our records that you have recently received a service from the [Admiral Nurses in Flintshire](#). As the service is new we are interested in evaluating it by gaining client feedback.

Would you therefore please kindly complete this brief questionnaire and return it in the stamped addressed envelope provided. You do not need to discuss this with the Admiral Nurse concerned if you are still seeing them and your comments will remain completely anonymous if you do not submit your name at the bottom of the form.

Please tell us in what way you were helped by the Admiral Nursing Service (tick one or more boxes):

I was given general support in the form of talking/counselling or listening to my worries.	
I was given written information about dementia	
I was given practical advice on managing a person with dementia	
I was given advice or assistance to claim allowances, council tax discount or grant monies.	
I was helped to get treatment for myself (e.g. medicines from GP).	
I was helped to get treatment for the person with dementia or the Admiral Nurse took an active role in monitoring the progress of the person with dementia.	
The Admiral Nurse provided a link to other helpful services such as the Alzheimer's Society, NEWCIS, Social Services etc	

If the Admiral Nurse did anything else above and beyond that listed please tell us what:

Please tell us overall how you would rate our service (*tick the appropriate box*):

Poor	Not very good	Satisfactory	Very good	Excellent

Please tell us about anything that you have found *particularly helpful*:

--

Would you recommend our service to anyone else caring for a person with dementia?

(Please tick appropriate box)

Absolutely not	Probably not	Maybe	Probably	Definitely

Please tell us *IF* there is anything that you think would improve the service offered to you.

*If you are happy for your nurse to receive your individual feedback please sign your name below. **If you wish to remain anonymous please leave this space blank.***

Your name _____

The name of the person you care for _____

Thank you very much for your feedback!

Appendix 2: List of comments from those who responded to the satisfaction questionnaire.

Comments

Duties provided above and beyond	Commented = 18
Nothing was too much trouble for the Admiral Nurse, everything she did was done in a cheerful and pleasant manner. There isn't enough superlatives in the dictionary to describe the way in which she carried out all functions.	
Help retaining admission for council house. Helpful in taking to hospital	
Helps to fill out claim forms, seems to know who/where to contact when needed. Always chatty and smiling which puts mum at ease.	
Was taken out form the house to get me in a new environment	
She provided practical and emotional support to myself as care at a time when I believed all other professionals failed to recognise my concerns regarding my wife's condition.	
Ginnette only started work in this area a short while before my husband died in July. She came a number of times and we spoke about my health and my husband's condition. I received a grant from Alzheimer's Society thanks to Ginnette. On the 24 th July she rang early to see how I was, I said my husband was very poorly, I had the Dr out the previous day, Ginnette came over straight away and stayed until after my husband passed away at 10.30 am. as I was on my own, my only son lives in the US.	
Ginnette provided advice and practical support re transport etc. She also assisted in a medication query, representing my views to medical professionals in an appropriate and successful way.	
Ginnette has been very helpful she has called out at night when I was taken ill and stopped with me and taken me to the hospital and has even offered to take me to her home and also taken my husband for a driving test to prove to him not to drive.	
Was available out of hours to talk to on the phone. Felt as though Ginnette was there 24 hrs	
Ginnette has been very supportive to my husband and myself, keeping in contact and I am able to ring here if problems arise, she works in a very professional way gaining full trust from my husband with his Dementia.	
Carol is most caring and supportive. We know that we can reach her at any time. Always available.	
Overall support and guidance was excellent at the onset of my fathers problems. She helped my mother with advice and is always most pleasant and informative.	
Takes us for all our hospital appointments	
Ginnette has been so kind and helpful in every way possible.	

Gave my daughter who lives in Derbyshire regular phone calls to discuss care and met her often when she came over.
Her visits lifted my spirits greatly.
The Admiral Nurse was so friendly she was like a family member. My mother and I both looked forward to her visits. I know if I have any problems I can phone her and she will do her utmost to sort them out.
Ginnette has and is a very wonderful, caring and helpful nurse.

Particularly helpful issues	Commented = 17
Assistance in allowances, council tax etc.	
Very helpful in helping me over bad patches	
Being able to contact Ginnette at any time to get help and advice	
I'm fortunate enough to have someone that takes time, quite regularly, to listen and assist with my concerns.	
She is a true professional. She goes about her duties with such dedication, offering structural and encouraging advice to myself and family. She acts as a liaison between myself and other healthcare professionals to ensure that my wife and I are receiving the appropriate medication and that all our healthcare needs are met.	
The grant that she accrued for me from the Alzheimer's was a godsend.	
All of the service, a very knowledgeable and professional individual - invaluable assistance, very helpful.	
Contact numbers, both office and mobile provided and regular visits as and when needed.	
Ginnette has been wonderful when I've been upset and I've had a heart attack 7 years ago and I did not know how to deal with it all, but she has been very good and explained to me what to do. Without her help I think I would not have been able to cope. I am 78 yrs old and I've never had such good service off any one. She is perfect for the job and well chosen for the position.	
Just feeling as though you are not alone.	
The way Ginnette and the consultant work together and communicate. Obtaining placement help and able to take myself to inspect the nursing homes also the help support with hospital appointments and her happy outgoing character.	
Carol provided an air cushion for my wife and has taken BP readings. We are grateful that she is accessible to us.	
Being able to talk to a nurse about any problems I have.	
My husband is in hospital for nine weeks and if I need someone to talk to Ginnette is there for me and I do appreciate that.	
Just to know someone other than family care about you as the doctor and nurses at the GP practice give no help what so ever.	
Taking our blood pressure and checking heartbeat.	

Hear easy friendly manner made it so easy to state our problems and needs and because she understood what was needed everything was sorted to our satisfaction.

Writing reports, filling in forms and generally looking after myself and wife, also discussions with Dr's on medications.

Suggestions/comments for improvement of service	Commented = 5
Faultless, is the only way I can describe the service. I cannot see how it can be improved except, maybe more visits but money will be the constraint. I wish you every success in the future.	
I don't know anyone around here with similar illnesses as the person I care for. Perhaps a meeting with my Admiral Nurse and a female in similar circumstances to me would open a window for me.	
I have found the service faultless any problems arising have been dealt with very professionally. I could not manage without the help. Thank you	
The service you give is excellent	
More nurses as they always seem to be so busy but Carol always has time to listen.	
You cannot improve on excellence.	

Appendix 3: email sent to a member of the Mental Health team in North Wales NHS Trust from a member of the Lotus Group, a service user/carer group from North East Wales.

From: *****
Sent: 26 September 2009 22:31
To: ***** (North Wales NHS Trust - Mental Health)
Subject: Admiral Nurses

Hi *****

Please disregard the email I sent on the 25th it was a draft that got sent in error.

The official email is below.

I was approached a few days ago by Mrs ***** from Flintshire, she was very distressed with a recent development with the support she is receiving.

Her husband ***** has suffered from Alzheimers for nearly six years. She has over the last 2 years had the support of an Admiral Nurse. The support has been extremely good. She has nothing but praise for the way that help has been given and she has come to rely on this service. She is very upset to have been informed that the Admiral Nurse is to withdrawn in the near future.

Whoever has made the decision to withdraw this support has obviously not had to care for someone with Alzheimers at home or they would realise that withdrawing this service from ***** would result in her being unable to have the ongoing advice and support that only a Dementia Special Nurse can give, as she would always talk to *****[carer] about ***** [husband's] change of behavior and how ***** [carer] should deal with the changes.

When cuts in services have to be made they must NEVER be made to the existing service user. The money must be saved by not starting the service for anyone new. The treating of someone with Alzheimers can gradually be adapted by the carer as the disease progresses but they need all the help they can get and NOT have any removed.

***** [name]