



Alzheimer Scotland
Action on Dementia

‘Please, send a doctor’

A Dementia Perspective on NHS Highland’s
Out of Hours Service.

*Involving people with dementia and their carers
in Highland Services*

August 2004



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1. Introduction

Out of Hours Services:

“Services that are provided by your GP and community health staff in the evenings, during the night, over the weekend and on public holidays”
(Caring for You Out of Hours, NHS Highland, 2004)

1.1. Background

In the Spring of 2004 NHS Highland indicated their intention to conduct a consultation between June and September 2004 about their proposed changes to the Out of Hours Service. To inform the public of their proposed changes they published the booklet ‘Caring For You Out Of Hours’ (NHS Highland, June 2004). In this they explain that change is required in response to the new contract for GP services that enables GPs to exercise their right to opt out of their responsibility for cover ‘out of hours’.

‘The aims of the new GP contract include the need:

- To introduce different ways of providing GP and other community health services, which meet the requirements of people and communities in 2004 and beyond
- To introduce more flexible working which *will improve services for patients* and give GPs reasonable working hours
- To pay GPs fairly for the work they do
- To improve recruitment and retention in the profession’

(Caring For You Out Of Hours, NHS Highland, June 2004)

NHS Highland expressed a wish to inform the public in Highland about the proposed changes and to get feedback about how these changes might impact locally throughout the region.

As part of Alzheimer Scotland’s strategy for ‘Involvement’, it was decided to participate in the NHS Highland consultation so as to provide *a dementia perspective* on the proposed changes to the Out of Hours service.

We decided to consult with people that we are in contact with throughout the NHS Highland area with a view to gathering together views about the proposed changes. We felt that people would be more likely to express their views to us based on our relationship of support and information fostered over time. Our feeling was that a collective voice, based on people’s experiences, would have greater clarity of message for NHS Highland.

2. Summaries of the Current and Proposed ‘Out of Hours Service’

2.1. The Current Service

In many parts of Highland, GP practices collaborate to provide an out of hours service. When you phone your doctor out of hours, depending on where you live, you will either speak directly with a doctor who will assess what action is required, or as in the case with Ness Doc, you will speak with someone at a treatment centre who will advise you on appropriate action. Where a number of GP practices collaborate it is rare that you are attended by your own GP out of hours.

However, in some parts of Highland, because of remoteness, local GPs provide the out of hours service for their own practice’s patients. Because of changes to the GP contract, all GPs are entitled to opt out of providing this round-the-clock service.

However, some GPs have decided *not* to opt out but to continue providing 24 hours cover because they feel the alternative presents an unacceptable deterioration of service for their patients.

2.2. The Proposed Service

In the proposed new out of hours service the initial contact will be by telephoning NHS24 (either by you phoning them directly or by automatic transfer from your GP’s number). Your call will be received by a call handler who will record details such as name, address, date of birth, reason for call etc¹. The call handler will then put you through to speak with a nurse advisor who will then conduct an assessment as to whether you require advice, to consult with a doctor (at a treatment centre or by means of a home visit), or to contact the emergency services. If you require to attend a treatment centre and have no transport then some will be provided.

It is anticipated that home visits will be greatly reduced and only available on the basis of ‘clinical need’. There has been a lack of clarity for the public about what constitutes clinical need. Will people with dementia qualify as having clinical need?

It is not only GPs who will be available to the public through the out of hours service, there will be community health staff too. However, little or no details have yet been given about the range and number of community health staff that would be part of the service.

2.3. In Event of an Emergency

With both current and proposed out of hours service, you should still dial 999 in the event of an emergency.

¹ Your first call to NHS24 requires them to register you on their system. This can be quite time consuming as they record information about medical history and medication as well as personal details, your GP’s name and address etc.

3. The Consultation Process

The Alzheimer Scotland Involvement Officer for Highland wrote a letter to service contacts explaining about the consultation and put together an information pack about the proposed changes to the Out of Hours Service (this included a copy of 'Caring For You Out Of Hours' and a leaflet about using NHS24). A response form was also enclosed (Appendix 1).

The Alzheimer Scotland Service Managers in Highland then assisted in the distribution of this mailing to their respective service contacts. The mailing was also sent out to any Alzheimer Scotland members in Highland not on these contact lists. A total of 480 letters were sent.

It was known beforehand that the contacts and members were a heterogeneous group consisting mainly of current and former family carers, but with a small number of people with dementia and some paid carers/ health professionals. As we had no previous experience of consulting across all our Highland services we decided to consult with all such parties with a view to learning from the experience.

People were invited to respond individually (in person, by telephone or by making a written submission using our response sheet), or through a group discussion at one of the organisation's Dementia Carer's Support Groups which meet regularly throughout the region.

4. Respondents' Profile

We received a total of 94 (20%) responses to the 480 letters sent out; 76 (16%) individual responses and 18 (4%) from Dementia Carer's Support Groups. Of these 94 responses, 38 (40%) were from people who gave no comment because they had not used the out of hours service in recent times (Appendix 2, Table 1). Many of these 38 responses indicated a willingness to be contacted again in a year's time to report back their experience of how the new service was operating.

This left 56 replies of which 11(20%) were positive or praised the new service and 45 (80%) that were critical and expressed concerns about the proposals.

Of these 56 respondents, the majority were female (86%); there were responses from throughout Highland; the responses from Badenoch and Strathspey and Ross-shire were increased by the involvement of 3 Dementia Carer's Groups; the proportion of responses increased with the age category of respondents (46% aged over 65); none of the responses were from people with dementia²; 59% of responses were from current carers.

² This reflects the content of the service managers' contact lists that were used and the very tight timescale available for consultation. It is hoped in future to build more contact with people in the earlier stages of dementia in order that they might participate more fully.

5. Consultation Responses ^{3 4}

We do not claim that the responses we received are statistically representative of all Highland carers of people with dementia. Clearly we have not contacted the sizable population of carers who have *not* been in touch with our organisation.

However, what we can present is rich, qualitative information rooted in the depth of personal experience of a considerable number of carers. In many instances their responses were detailed, carefully considered, insightful and sometimes poignant.

Despite some very upsetting experiences, carers are rarely willing to consider any formal complaint. Generally they tend to be fearful of ‘making things worse’ for those they care for but are also respectful of professionals, valuing their expertise. Carers often feel an enormous sense of responsibility for those they care for.

They take their role of carer very seriously and often require considerable encouragement and support to request assistance. Carers of people with dementia tend to be older, not infrequently in their 80’s and 90’s themselves, and often have their own health issues to cope with in addition to caring for someone with dementia.

With the exception of one response listing both advantages and disadvantages of the proposed out of hours service, the responses we received tended to be *either* positive and offering praise *or* concerned and offering critical comments. Although some responses were based on people’s perception of how the proposed service might impact on people with dementia and their carers, most were grounded in their personal experience of using the service recently.

5.1. Comments that were positive and/or praised NHS24 and the Out of Hours Service:

5.1.1. A Prompt Service

Some carers were impressed with the promptness of the response they received:

‘I have used the NHS24 service and I was surprised at the promptness and courtesy I received. Certainly no complaints so far’

and

‘I have only had to use the service once so far when my wife would not settle. A doctor came quite promptly and gave some pills.’

³ It varies across Highland as to how many components of the proposed new service are already in place. Some respondents were able to comment directly on their experience of using NHS24, of attending treatment centres and of attempting to get home visits.

⁴ Although we are reporting from a dementia perspective, it should be noted that the majority of reasons for the respondents needing assistance out of hours was not directly relating to dementia, rather some physical illness. Nevertheless dementia impinges on all aspects of carers’ use of the out of hours service, whether for themselves or for those they care for.

One carer reported that NHS24 arranged for a doctor to visit when her mother experienced severe abdominal pain:

'A very helpful lady from Glasgow informed me that doctor would visit within 4 hours and would not hear of mother having to attend a treatment centre because of her age and dementia. A doctor arrived within 1 hour and suggested we take an ambulance to the local hospital'

Another carer reported that she was very impressed with the service: she had phoned for advice and been reassured by the nurse advisor. Also when her daughter phoned on her behalf an ambulance was sent and she was promptly admitted to hospital.

One carer had used the service twice in the last month (June 2004):

'I've found it very satisfactory although your call is put through to Aberdeen. Within a short time you are in contact with a nurse who takes all your details. Definitely, it would be an improvement if you were able to speak to a local person. However, the service was very good.'

5.1.2. An Efficient Service

In addition to the speed of response, some carers reported on the service's efficiency:

A carer reported that when the doctor was delayed in attending her, NHS24 phoned her back to let her know. She thought service was very good and a great comfort.

Another carer said

'At least you won't get an answer-phone or be told to phone a series of other numbers.'

5.1.3. A Helpful Service

Some carers felt very grateful for the help they received:

A carer reported that he had used the out of hours service for his wife and himself:

'The medical ambulance and Ness Doctor services are very helpful in this area. The knowledge that there is help and advice out there during the wee small hours is a comfort to those who have loved ones to look after, with advanced dementia.'

And another carer said:

'I have called NHS Highland Out of Hours Service twice concerning my 93 year old mother, both times they have been very helpful.'

A carer reported that she felt that the service would be of so much help to herself and others who sometimes have difficulty in getting help.

5.1.4. Good for Advice

In one carer's opinion people may be more likely to phone NHS24 than their doctor for advice out of hours because they do not want to trouble the doctor.

5.2. Comments that were concerned about or critical of the service

5.2.1. Carers Concerned

Some carers were generally concerned about the proposals, both for themselves and those they cared for:

'As someone over 65 and living alone I am greatly concerned about the NHS Highland proposals'

and

'All my life I have worked hard and paid my dues, I feel that I shall be failed as the twilight of life approaches'

and

'what they are proposing is a bit alarming'

5.2.2. The Phone Call

Some carers reported that their call was not transferred automatically to NHS24:

'I phoned my GP and got a message saying to phone this other number. I had to go and find some paper and a pen to copy down this long number. All I wanted was to speak to my GP.'

Except for doctors *not* opting out, will all out of hours calls be automatically transferred from a doctor's surgery to NHS24 from January 2005?

One carer felt that getting through to a call centre would be confusing for a person with dementia:

'Someone with dementia when phoning their doctor's number expects to speak to their doctor and not a call centre.'

5.2.3. The Amount of Information Requested

Many respondents reported being frustrated by the amount of information they were asked for and felt it got in the way of their reason for calling:

'They asked too many questions, it takes up too much time'

and

'Luckily I was able to answer all the questions I was asked but I appreciate it would have been very difficult if it had been a friend or neighbour with my sister and they were asked about date of birth, tablets etc.'

and

'Would Alzheimer patients living alone be able to cope with a strange voice asking a lot of strange questions? I think not.'

and

'A carer desperate for help will be fully occupied trying to cope.'

If the public register with NHS24 when they are well and not requiring help, will this speed up the processing of their call when they do need assistance?

5.2.4. Repeating the Information

Many respondents were frustrated at being asked the same questions repeatedly:

'All the lady could do was ask questions. I kept pleading for a doctor but she persisted with her question. Then she said she would pass me to a nurse, who then started asking the same questions again. She asked was my wife conscious or was she breathing, "How the hell do I know – she is in another room and I am stuck here answering your questions twice". She said she would inform the doctor. Then the doctor phoned and he asked the same questions again and then he visited.'

and

*'Thirty minutes after a GP had visited, **** collapsed. We tried contacting NHS24 a second time and they insisted on going over all the same procedure as before. We cut short the call and called the ambulance.'*

Can NHS24 review procedures to try and reduce this repetition of information requested?

5.2.5. Relevance of the Information

Some carers questioned the relevance of the information requested;

'I was in tears pleading for a doctor and she asked me, "How long have you lived in the area?'"

and

'People do not want to answer bureaucratic questions when their perception is a need for medical attention'.

5.2.6. Call Refused

One carer reported her distress and frustration when NHS24 refused to accept her call:

*'The call handler refused my call at first because my father was in residential care, even though I have Power of Attorney. NHS24 said the care staff must phone. The nurse went on the phone and backed me up so **eventually** my call was accepted.'*

Carers and relatives do not stop having a sense of responsibility for the person they care for just because they are in residential care. Ideally, any action they take will be in co-operation with staff of the residential home, but [where do they stand if there is disagreement?](#)
[What are the guidelines for accepting/refusing calls?](#)

Other carers have reported their call being refused because they were not physically with the person needing help. There are sound reasons why it is preferable for the caller to be with the person needing help so that they can pass information to the nurse advisor about symptoms. However, some people with dementia live alone with support from family at a distance. If their carer's call to NHS24 is refused then the only other alternative would be to phone 999 for a situation that might not merit the emergency services.

[When a person with dementia has managed to phone a relative for help what should the relative do?](#)

5.2.7. Medical Judgements

Some carers feel they are being asked to make a 'medical judgement' about whether the person they care for needs emergency admission or whether a person with dementia is fit to travel to a treatment centre. This is linked to not being able to speak directly to a doctor who knows the patient

'Quite often I was not sure if I needed a doctor or not (for the person he cared for) and on more than one occasion I misread symptoms to the detriment of my father who ended up going into hospital because of it.'

and

'They (the nurse advisor) will be relying on a description of the symptoms from a non-medical person - how reliable will this be?'

and

'If they could even dispatch a nurse to the patient who cannot travel.....at least if the nurse attends and cannot sort out the problem then you really do know that you need a doctor, who can then be briefed by the nurse.'

5.2.8. People with Dementia Using the Service

Some carers were concerned that the new system would baffle people with dementia when calling on behalf of themselves or the person who cares for them:

'People have been used to contacting their doctor when they are ill. A person with dementia could be confused by the new system,it requires concentration to answer all the questions.'

and

'My brother lives alone and suffers from dementia. I do not feel he would be able to cope with the new system (of out of hours). He would not understand if someone fired a lot of questions to him down the phone'

and

'the system might work with two responsible adults in the house, but not if one has dementia'

and

'people with dementia can give plausible answers that are quite incorrect'

5.2.9. Delays with NHS24

Several carers experienced a delay in getting assistance because of their call being processed through NHS24. They reported delays in getting action because of too many questions and too many stages in the process from making an initial call through to speaking with a doctor in person, or them phoning back, or a visit:

'Please, send a doctor, then I'll answer your questions'

and

'Vital time is wasted giving details followed by a return phone call repeating word for word what has just been said to the person answering the first call.'

and

'I felt there was quite a long time spent between the call being answered and a decision taken as to what we had to do but once at the hospital the treatment was very good.'

and

'With all these questions it took three-quarters of an hour for the doctor to arrive. If I could have phoned him directly he'd have been here in 7 minutes.'

5.2.10. Delay in Getting Advice or Treatment

Some carers found the system was not responsive to situations that were serious but not necessarily requiring emergency 999 or hospital admission:

'My father was in severe pain and I was told the doctor would be there within the hour but it took 2 hours and 3 calls to NHS24 for the doctor to arrive.'

and

'If I'd been able to speak with doctor directly it would have saved a lot of time and a lot of suffering.'

and

'it took a wee while to go through all the questions then I was told the nurse was busy and she would phone back. She didn't, so I phoned back and had to go through it all again, meanwhile my husband was in pain.'

One carer reported that it took from lunch-time when she made the call until 7pm for her husband to reach Raigmore, and he was choking during all this time.

One carer pointed out that elderly people are likely to need to have transport provided and that this might lead to further delays if drivers are covering several calls over a wide area.

5.2.11. The Delay in Home Visits

Some carers experienced delay in getting assistance because duty doctors are not familiar with where the patient lives:

'The doctor came from Golspie and didn't know us, he had quite a job finding the house, I was getting a bit panicky, our own doctor would have known us'

and

'the GP was from another area and went past the house 3 times'

5.2.12. Travelling to a Treatment Centre

Some carers were worried about how they would get a person with dementia to a treatment centre and the delay involved:

'I can't imagine my husband travelling to a treatment centre in the middle of the night, he can be very stubborn'

and

'I've looked after my husband for 9 years, I do everything for him and I feel we need something locally, not having to travel 15 miles through to Inverness in the middle of the night'

Can NHS Highland and NHS24 review all aspects of delay with a view to reducing the bureaucracy and speeding up the response?

5.2.13. Knowing the Doctor and the Doctor Knowing the Patient

Many of the concerns raised by our respondents were interlinked, particularly to the importance of the patient-doctor relationship. There was huge strength of feeling expressed around the issue of having access out of hours to a doctor who knows the patient. Particularly for the older generation, health issues can become complex and multi-layered and great value is placed on knowing the doctor and them knowing you - for medical as well as social and emotional reasons:

'At one time those at the end of the telephone knew me!!!!'

and

'There are 4 doctors in my practice, surely they could take turns to provide out of hours cover, then they would know the patient'

and

'If the doctor doesn't know you then you end up going over the same ground again and again, having to explain things over and over'

and

'Any phone call for help needs to be made to someone who is already aware of the circumstances, as is the case at present when people call their own medical practice.'

and

'The doctor who arrived did not know anything about my sister. My sister then became very agitated when she was examined by someone she had never seen before'

and

'The problem is, you the carer have to be able to recall the patient's medical history for the attending out of hours doctor as they don't have direct access to it. The patient with dementia may not be able to do this or may mislead the doctor without realising it.'

and

'They (NHS24) are not going to know if the caller constantly phones their GP about minor problems or whether they would only call when they were really desperate'

and

'Should an elderly carer require assistance 'out of hours', then they need to speak to someone they know'.

and

'A GP who is a stranger will have difficulty communicating with them (a person with dementia) and understanding the problems.'

and

'having to make a lengthy telephone call to strangers and explaining things already known by one's own GP team is the last thing a lone carer needs'.

One carer felt that in her experience the visiting doctor may be less likely to initiate a change in care management if the patient is not one of their own:

'The doctor just prescribed some painkillers and said he should see his own doctor on Monday. They were not effective so my father suffered for another 36 hours until his own doctor prescribed appropriate painkillers for his cancer.'

Can NHS Highland please listen to the very clear message that where possible, people prefer to be seen by their own doctor or failing that, by someone from their own practice, and failing that by someone from their local area?

5.2.14. Dementia Remains Hidden

A number of respondents expressed concern that for someone with dementia calling on behalf of themselves or indeed on behalf of the person who cares for them, dementia may not be obvious in the course of a telephone call for assistance. This could lead to inappropriate handling of the call, inappropriate advice or instructions being issued and increased risk for the person with dementia.

'A person with dementia might give the impression that they have no difficulty understanding instructions and might give the wrong information'

and

'They might not get the appropriate assistance because by telephone it would be difficult to ascertain that the person has dementia'

and

'They may not say what they mean or be able to convey the problem, they may well forget or not know why they are there at all.'

5.2.15. Highland Geography

There was a lot of concern about the size of area that one GP was to cover after midnight, particularly in winter when weather can be severe and snow can block roads:

'One GP (after midnight), covering a vast area - Drumnadrochit to Cromarty, cannot be in two places at one time and will therefore be reluctant to travel too far to see one patient leaving the remainder of the area uncovered.'

and

'It seems quite ridiculous that in Badenoch and Strathspey, only one GP from Inverness could be on call. It is a huge area with particular weather problems in winter.'

and

'if there is a flu epidemic are the doctors on call going to be increased?'

and

'Doctors are entitled to a life but could groups of GP practices not operate a shift system locally so they and we did not have to travel so far for treatment, also so that they do not have to work the next morning?'

and

'Doctors shouldn't have to travel these distances in winter when the roads are dangerous and neither should we.'

Carers feel that doctors face enough difficulties locally in winter without having to travel the distances proposed in 'Caring For You'.

Negotiation with GPs has continued throughout this period of consultation rendering some of the information in 'Caring for You' out of date. Will NHS Highland publish details of the new local arrangements across all of Highland as soon as possible?

5.2.16. Home Visits for People Coping with Dementia

In 'Caring for You' it states that although it is expected that the number of home visits will reduce, they will still be available 'based on clinical need'. Some carers doubted that they would be available given the numbers of GPs on duty over such a large area; also they were concerned about what constituted 'clinical need':

'I believe that home visits will be unlikely.'

and

'I feel if the patient has dementia they should get a home visit and the carer should not have to plead for one.'

and

'It was made clear that they would be very unwilling to get the doctor to do a home visit and stressed that you would have to come to the local hospital and wait in the waiting room along with others waiting for the doctor.'

and

'It is hard enough to get someone with dementia dressed, out of the house and into a car when they are well.'

and

'People with dementia should be looked after at home if possible. If they are feeling ill, they need a doctor to come to them as they are probably very confused. So if they are put into a car to travel goodness knows how far, that is not good patient care.'

Can NHS Highland assure carers that if their circumstances require it, then a home visit will be offered?

Can NHS Highland assure carers that sufficient GP's will be on duty to provide home visits?

5.2.17. Red-flagging

The NHS24 system has a facility to 'flag' patients with particular needs, risks or circumstances:

Health and social work staff reported to us that in their areas (Easter Ross and Lochaber) some GPs have expressed willingness to 'red flag' patients with dementia on the NHS24 system.

Is this practice of flagging people with dementia happening throughout Highland?

How many people have been flagged for dementia?

What about the many people with dementia who have not received a formal diagnosis?

A respondent reported that her doctor had said that she should be notified to NHS24 as particularly at risk because of her medical condition. When she was in touch with NHS24 some weeks later, there was no information available about her condition.

What checks are there on the system to ensure the necessary flagging is done?

5.2.18. Training

Some carers highlighted the need for all staff to have specific dementia training - call handlers, nurse advisors, GPs and drivers:

'they may have absolutely no experience of dementia and know nothing of the sorts of problems which can arise, thinking it is just a matter of being a bit forgetful. Consequently the advice they offer may be quite unsuitable.'

and

'There is little enough understanding of dementia even with the professionals. Trying to explain to a GP who has little knowledge of it in an emergency will add considerably to the distress.'

and

'I have discovered just how little real understanding there is of the effects of dementia on sufferer and carer. Ideas among friends, relatives and some NHS personnel can be woolly or preconceived (if the illness is even thought about at all). It might be reassuring if the nurse advisor had specialist knowledge and a real perception of the scenario at the other end of the telephone.'

Carers felt it was wrong to assume that medical qualifications indicated adequate preparation for dealing with dementia issues.

What dementia-specific training is provided and to whom?

5.2.19. Mental Health Service Out of Hours

Some carers experience difficulty when the person they care for becomes agitated, distressed and occasionally violent:

'I was then advised to call the police (by NHS24) who in turn refused to come as they were too busy. Two and a half hours later a GP called after we had suffered 4 hours of abuse and aggression. We also discovered that (in Inverness) there is no mental health emergency cover over the weekend period.'

What out of hours mental health service is there throughout Highland?

How does the GP out of hours service link with the mental health out of hours cover throughout Highland?

5.2.20. The Proposed Model

Some carers commented on and questioned the structure of the proposed model for an out of hours service:

'NHS24 is good for advice but they have stretched it too far in getting it to co-ordinate the Out of Hours Service.'

and

'It is no use using average figures, the system needs to cope with extremes.'

and

'The proposals (for the Out of Hours Service) conflict with other policy initiatives such as "Care for the Elderly" and "Care without Barriers".'

and

'it exacerbates difficulties for the hard of hearing when they have to answer so many question by people who do not know them'

Two carers in the Invergordon area reported that they had encountered difficulty and delay in getting help because their **postcode** was not recognised by the NHS24 system. They have reported their difficulties to the post-office who have confirmed their postcodes are valid. They are not in new properties (one carer has lived there for 18 years). Unfortunately, one of these carers reported that her husband died while she was pressing NHS24 to accept her call.

Can NHS24 sort out the issue of postcodes not being recognised by their system so that unnecessary delays do not occur?

A carer queried whether, if you need to be seen by someone, there was a time limit within which you should be seen by a GP or other team member.

A carer was concerned that a lot of money was being spent on what is effectively a reduction in service with fewer GPs available.

Some carers were concerned that their own GP would not know about the outcome of their contact with the out of hours service. They queried whether their GP would be automatically informed by the out of hours service of their contact with the service and the action taken/medications prescribed etc.

[Does NHS24 and/or the out of hours service inform GPs of their patient's contact with their service?](#)

A carer reported that she found the NHS24 staff condescending.

It is not just people with dementia who do not understand the system. We had several reports of people turning up at Raigmore and being refused service, even when the duty doctor was not consulting with anyone, because they had not made the initial call to NHS24.

5.2.21. Bad Advice or No Advice

Two carers reported their experience of the system simply did not work as it should:

A carer reported being given incorrect advice with regard to dealing with an unconscious relative.

Another carer reported that she arrived home to find her husband (who has Parkinson's and dementia) had taken too much of his medication. She phoned NHS24 and went through the whole process until she was put in touch with the duty doctor. The duty doctor said she wasn't able to help as she knew nothing about Parkinson's. No help was offered and the carer sat up all night with her husband to watch over him.

Carers expressed concern about the negative consequences arising from the proposals:

5.2.22. Increased Use of Emergency 999

Several carers expressed concern that use of the emergency services would increase:

'I believe that people will soon revert to 999 or just turn up at the nearest accident and emergency department in person.'

and

'I think there will be a strain on the ambulance service.'

and

'999 are going to be harassed'

and

A carer listening to a friend phoning NHS24:

'I'd have given up and phoned 999'

and

'As well as dementia, my husband is diabetic and disabled. I phoned at 2.30am one night when he was ill and they said "can you take your husband to Dingwall", I mean, I'm not young and don't keep that well myself to be driving miles through the countryside in the middle of the night. Next time I'll be more inclined to phone 999.'

and

A carer/health professional reported that already, 999 calls were on the increase as people lost patience with the delays in getting a response to their initial call to NHS24 and that this is leading to longer queues in Accident and Emergency.

[Is NHS Highland planning to monitor levels of use of emergency services following the pan-Highland introduction of the new out of hours service?](#)

5.2.23. Carers' Health and Well-being

Some carers reported that use of NHS24 and the out of hours service had made life more difficult:

'I was grossly frustrated'

and

'I felt very, very angry',

and

'I was in tears pleading for help'

and

'If they have to travel to a treatment centre in the middle of the night their stress levels will definitely increase and may exacerbate the whole problem'

and

'Life can be very difficult for relatives, (of people with dementia) if changes in health arrangements cause anxiety it would be a cause for concern as often the carers are frail themselves.'

5.3. One Carer's response

Many of the points made by our respondents were captured in one person's response to our consultation and so we include it in its entirety:

"When my late husband (he suffered from dementia) lived at home, before going into a Nursing Home, our doctor said to me, "Remember I'm always at the other end of the phone if I'm needed". How different the situation will be if the new proposals are implemented. It could take a considerable time to get through all the questions which will be asked by the one receiving the calls in NHS 24, then someone in authority has to assess the problems of a complete stranger. If the decision is to send a doctor, he or she will have to travel from Inverness, quite a long way, and if the weather is bad this could be very difficult. On arriving in Grantown it could be a problem finding the house. If the decision is to visit a centre, which for here I believe is Aviemore, transport will be provided. It does not state if this is an ambulance, a taxi or a volunteer driver. This must need clarification.

Now that I am on my own and elderly I have grave concerns. If I am ill I may not be in a fit state to answer all the questions. If a car or transport is to be sent to take me to a centre I may need help to dress and be ready for the journey.

One or two general points:

In our area of Strathspey many patients may live in the country. It is going to be extremely difficult for a doctor to find his way – coming from Inverness.

How many doctors will be on call in Inverness? It does not say. There could be long delays waiting for a doctor. Would it not be better value for money to have a local doctor on call? With a rota system and the number of doctors in Grantown, Aviemore and Kingussie, night cover duty would not come around too often.

What happens if the roads are blocked with snow and frost during the winter months?

Another point, there could be an accident on the A9 or there could be an emergency on the hills. What is the answer to these problems? Again the time factor comes in.

Finally, a friend of mine in Grantown, whose husband became ill about 9pm, rang NHS 24. After all the questions were answered she was put through to a nurse who told her to give him 2 painkillers and ring back in 2 hours. She was not happy and her daughter jumped the gun and called their doctor. He came, and inside the 2 hours her husband was on the operating table in Raigmore. His life was saved.

One last point: the 999 services may get upset if too many people call them thinking their case is an emergency."

(Name provided)

6. Conclusion

6.1. Comments on the Consultation

As an organisation Alzheimer Scotland is interested in working collaboratively with other agencies to involve people with dementia, carers, patients and the general public in service planning and development.

Alzheimer Scotland in Highland decided to participate in this NHS Highland consultation with a view to presenting a 'dementia perspective' on the proposed out of hours service. We felt that we were well placed to tap into a sector of the public with a wealth of personal experience of living and coping with dementia issues. It was a new venture for us, made possible by the existence of the post of Involvement Officer in Highland. Our participation was also only possible because of the supportive contact that Alzheimer Scotland Service Managers have established with people with dementia and their carers across Highland.

NHS Highland and NHS24 were very efficient in their response to our request for nearly 500 copies of their booklets and leaflets. We would like to make the following comments about the content of 'Caring for you Out of Hours':

- NHS24 was referred to throughout the booklet but the number to ring was never given. We feel this was a missed opportunity to provide the information and led to some confusion in those reading the booklet.
- When phoning NHS24 we are told that a qualified nurse will take our details and talk us through our symptoms. No mention is made of the call handler. This is a major omission given the level of discontent expressed by people using NHS24 about this aspect of their phone call.
- The table on page 10 provides information about the proposed new arrangements for Highland Towns and catchment areas. However, discussions between GPs and NHS Highland have been ongoing throughout the period of consultation. We were aware that local arrangements were being negotiated but received no updated information about these. It felt like the goal posts were moving throughout the consultation and that they will continue to do so beyond the deadline for consultation.
- We are told that in addition to GPs, a range of specialist staff – midwife, community psychiatric nurse, paramedic or specialist primary care nurse - will be involved in providing a range of services out of hours. However, no details about how many, when and where are provided to comment on.
- Pages 12 and 13 deal with rural communities in Highland. We found that the public were confused by the information provided as to whether patients of GPs *not* opting out (i.e. those GPs continuing to provide round the clock service to their patients) should still phone NHS24 as the first step to getting assistance. The information on page 13 seems to suggest they should phone NHS24 first, but one GP who is not opting out suggested they should just phone their GP as at present.

6.2. Recommendations arising from the consultation

We would recommend that:

- NHS Highland publish in detail the modified GP cover arrangements that have been negotiated across Highland, including an updated list of practices/ GPs not opting out.
- NHS Highland provide details of the range, how many and when staff other than GPs, will be available through the out of hours service.
- Once arrangements are finalised, every patient in every practice (opting in and opting out) should receive clear instructions as to the steps they should take if they require assistance out of hours, with a description of the service available to them.

6.3. Questions for NHS Highland and NHS24

Carers' responses in section 5.2 gave rise to questions for NHS Highland and NHS24. These are brought together in this section. We would request that NHS Highland provide a written response.

1. Except for doctors *not* opting out, will all out of hours calls be automatically transferred from a doctor's surgery to NHS24 from January 2005?
2. If the public register with NHS24 when they are well and not requiring help, will this speed up the processing of their call when they do need assistance?
3. Can NHS24 review procedures to try and reduce the repetition of information being requested?
4. If carers/relatives wish to call for assistance for a relative in a residential care home are they entitled to do so?
5. What are the guidelines for accepting/refusing calls to NHS24?
6. When a person with dementia has managed to phone a relative for help what should the relative do?
7. Can NHS Highland and NHS24 review all aspects of delay with a view to reducing the bureaucracy and speeding up the response?
8. Can NHS Highland please listen to the very clear message that where possible, people prefer to be seen by their own doctor or failing that, by someone from their own practice, and failing that by someone from their local area?
9. Negotiation with GPs has continued throughout this period of consultation rendering some of the information in 'Caring for You' out of date. Will NHS Highland publish details of the new local arrangements across all of Highland as soon as possible?
10. Can NHS Highland assure carers that if their circumstances require it, then a home visit will be offered?
11. Can NHS Highland assure carers that sufficient GPs will be on duty to provide home visits?

12. Is the practice of “red-flagging” people with dementia happening *throughout* Highland?
13. How many people have been red-flagged for dementia? What about the many people with dementia who have not received a formal diagnosis?
14. What checks are there on the system to ensure the necessary red-flagging is done?
15. What dementia-specific training is provided and to whom?
16. What out of hours mental health service is there throughout Highland?
17. How does the GP out of hours service link with the mental health out of hours cover throughout Highland?
18. Can NHS24 sort out the issue of postcodes not being recognised by their system so that unnecessary delays do not occur?
19. Does NHS24 and/or the out of hours service inform GPs of their patient’s contact with their service?
20. Is NHS Highland planning to monitor levels of use of emergency services following the pan-Highland introduction of the new out of hours service?

6.4. Discussion

Some people’s use of NHS24 and the out of hours service has proved to be very satisfactory. They experienced a prompt, efficient and helpful service.

Unfortunately this was not everyone’s experience. In response to this consultation we heard of many distressing instances of frustration and concern. Some carers experienced delay in getting assistance because of phoning a call centre and all that entailed, rather than speaking directly with their doctor.

The doctor/patient relationship is greatly valued and considerable regret was expressed at the breakdown of communication with and care provision by a doctor known to the patient. Many carers were daunted by the prospect of trying to take a person with dementia to a distant treatment centre in the middle of the night. Many carers were also concerned about whether they would qualify for a home visit and whether there would be enough doctors on duty to provide a home visit.

Carers highlighted the need for dementia-specific training throughout the service to enable staff to respond appropriately. Carers were interested to ensure that where appropriate, the flagging facility was used for people with dementia. Some carers were concerned about the links between the GP out of hours service and the mental health out of hours service, plus the gaps in cover provided by the latter. Many carers held the view that the proposals would result in increased use of the emergency services.

We submit these comments, recommendations and questions to NHS Highland for their consideration and response.

Appendix 1

Response form

Please return this form before Monday 16 August 2004

to:

Sheila MacIver
Involvement Officer – Highland
Alzheimer Scotland
3 Gordon Terrace
INVERNESS IV2 3HD

or telephone 01463 711710/711707
or email: smaciver @alzscot.org



Changes to NHS Highland Out of Hours Services – Consultation

Please use this sheet to tell us about any experience you have of using the Out of Hours Service in the last year and any thoughts you have about how easy it will be for people with dementia and their carers to use the proposed service.

(please continue on a separate sheet if necessary)

To assist with the analysis of all the feedback, please tick all the boxes that apply to you.

Gender: male female

Resident in: Badenoch & Strathspey Caithness Lochaber Nairn
Ross & Cromarty Skye and Lochalsh Inverness Sutherland

Age range: under 20 years 20-50 years 51-65 years over 65 years

Are you?

- A person with dementia, living on your own
- A person with dementia, living with others
- A carer/relative of a person with dementia
- An ex-carer/relative of a person who had dementia
- A professional working with the dementia services

Your contact details:

Name.....

Address.....

.....

Telephone.....

Email

Would you be willing to be contacted again next year to gather feedback once the service has been running for sometime? YES NO

If in the meantime you have any experience of using the Out of Hours Service that you wish to share with us, please do not hesitate to contact us.

Any information you provide would be treated in confidence; your name and address will not be passed on to NHS Highland without your permission.

Appendix 2

Profile of respondents and summary of responses

Table 1 Summary of responses to Out of Hours Consultation by Alzheimer Scotland

		Praise/ Positive	Concerned/ Critical	Sub-Total	No Comment/not used service yet	Total
Total		11	45	56	38	94
Gender						
	Male	2	6	8	6	14
	Female	9	39	48	31	79
Area						
	Badenoch & Strathspey	0	13	13	1	14
	Caithness	1	2	3	5	8
	Lochaber	1	2	3	6	9
	Nairn	0	1	1	3	4
	Ross and Cromarty	2	16	18	7	25
	Skye and Lochalsh	1	1	2	4	6
	Inverness	6	7	13	8	21
	Sutherland	0	3	3	2	5
Age						
	0-19	0	0	0	0	0
	20-50	1	11	12	3	15
	51-65	5	11	16	13	29
	>65	4	22	26	19	45
Respondent						
	Person with dementia	0	0	0	0	0
	carer	8	25	33	24	57
	ex carer	3	19	22	10	32
	Paid carer/professional	0	1	1	3	4

(When figures do not add up to totals, it is because of missing data where boxes were not ticked)



Alzheimer Scotland

Action on Dementia

Buidheann na h-Alba airson Seargadh-Inntinn
Gníomhadh mu Seargadh-Inntinn

Alzheimer Scotland – Action on Dementia is Scotland's leading national voluntary organisation to support people with dementia and their carers. Membership is open to all individuals, community groups, professional associations, service providers and corporate bodies.

Our aims are to

- represent the interests of people with dementia and their carers
- promote the provision of high quality services for people with dementia and their carers
- provide high quality services for people with dementia and their carers

What we do

- campaign nationally and locally for better services
- provide a freephone 24 hour **Dementia Helpline: 0808 808 3000**
- provide carer education and support
- run nearly 50 local specialist services for people with dementia across Scotland including day care, home support and counselling
- provide an information service and website: **www.alscot.org**
- carry out research on service provision and other aspects of care
- raise public awareness through our branch network and other activities
- fundraise to support our work
- provide opportunities for volunteers

For further information about membership or any of our activities please contact:
Alzheimer Scotland, 22 Drumsheugh Gardens, Edinburgh, EH3 7TN.
Telephone 0131 243 1453. Fax 0131 243 1450.

or

**Alzheimer Scotland, Highland, Western Isles and Orkney Regional Office,
3 Gordon Terrace, Inverness IV2 3HD.
Telephone 01463 711707. Fax 01463 711715**