

A review of free personal and nursing care

Report supplement: Results of focus groups with older people



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Auditor General for Scotland

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Part 1. Introduction

1. This supplement accompanies Audit Scotland's report, *A review of free personal and nursing care*, and summarises the main findings from focus groups of older people and their carers. The focus groups were commissioned by Audit Scotland and carried out by Age Concern Scotland.
2. Age Concern Scotland's remit was to report:
 - the financial effects of the free personal and nursing care (FPNC) policy on older people
 - older people's and carers' experiences of access to and quality of FPNC services, both within care homes and at home
 - older people's and carers' views of whether the introduction of the FPNC policy has changed access and eligibility to other services, eg domestic support such as help with household cleaning.
3. Ten focus groups were facilitated across Scotland, in Dumfries and Galloway, Edinburgh, Fife, Glasgow, Highland and Perth and Kinross. Fifty-eight older people aged over 65 years and three of their carers participated in the focus groups. Almost all were aged over 70 years and the majority were aged over 80 years. Forty-seven of the participants were female and 11 were male. Focus group participants were either receiving care services or had been assessed for these services. This included a significant number who could be expected to be receiving FPNC.
4. The report summarises what older people attending the focus groups told Age Concern Scotland. **Appendix 1** contains quotes from older people attending the focus groups.
5. Some of the findings from the focus groups are included in the full report.

Part 2. Focus group feedback

6. Age Concern Scotland's facilitators set some broad questions for older people and the responses are reported below. The responses are grouped into those made by older people living in their own home and those living in care homes.

General comments

7. There was a very low level of awareness of the FPNC policy, including amongst those who were known to be in receipt of FPNC. There was evidence that some older people believed that free personal care was a different service from home care and was provided by different people. This was more apparent where a home-from-hospital service had been provided by a different 'team' immediately following discharge from hospital and was provided free of charge for a set period (usually between two weeks and a month). There was a very strong view that the home-from-hospital service was provided as a matter of course – no-one had to ask for it, whereas there was a general belief that FPNC had to be requested. Not all council areas have home-from-hospital services. Reluctance to ask for help featured in discussion at every focus group. Carers expressed concern about unrealistic expectations of carers by both councils and family members. A number of people expressed a preference for their family to provide care but it was unclear if family were actually able to do this.
8. Many of the participants did not know how much they paid for care and other services and what they were actually paying for. Many found the paper work too complicated. The carers who were present all confirmed they handled the paperwork, assessment and financial aspects of their family member's care. One carer stated she had not heard about FPNC.
9. A number of participants had been advised by their council to apply for attendance allowance to help pay for domestic type services but usually completed the form themselves. Where an application for attendance allowance was refused it put the individuals off applying for any other help. A small number of people believed that attendance allowance recipients (living in their own home) could not receive FPNC as well. One person believed that being in receipt of attendance allowance or disability living allowance meant automatic entitlement to FPNC.
10. The main assistance individuals were receiving was bathing, showering, meal preparation and dressing. Some focus group members recalled that nurses used to provide bathing and other services free through the NHS and questioned why this has been changed.

Question 1: What financial difference has free personal and nursing care made to older people?

Responses from older people who live their in their own home

11. One lady was paying £100 less a month for help with bathing which she had previously been charged for.
12. Two community-based focus groups reported positively on the financial benefits of FPNC. One person now receives a regular service which she does not have to pay for – whereas before her service had been intermittent when she did pay for it.
13. Those who said they were financially worse off had mainly been receiving domestic help previously through the council and the charges had been significantly increased – some by as much as 30 per cent with one person reporting an increase of 50 per cent. Over half of those affected had gone on to arrange their own domestic help privately. A small number had done this because they wanted the freedom to arrange their own domestic help and get what they wanted when they wanted. Others employed someone locally because they either could not afford the higher fees or they were not prepared to pay “exorbitant” costs.
14. A small number of people had refused personal care once they knew they had to be assessed. A number of people who had received a free service following discharge from hospital refused to have it continued beyond the free period because they were either going to be charged or thought they were going to be charged. There was evidence of poor information about access to FPNC at this stage.
15. In locations which experienced higher levels of pensioner poverty hardly anyone noticed a difference in how much money they had left over to spend as they had received free services before the introduction of FPNC. This had been because of their low levels of income and savings. Their issues were more about access to services rather than cost.
16. Minority ethnic elders are not accessing FPNC because they said they do not know about it and are much less likely to approach statutory agencies for help. This is partly because there is a shortage of care workers who can speak Chinese or other languages and cultural differences make some practices unacceptable, eg the bathing of female clients by a male care worker.

Responses from older people living in care homes

17. Care home residents who contributed to their own care home costs reported higher levels of financial benefit although there were a number of individuals who were still concerned that any future decline in

their physical or mental health could result in them having to pay more. This was identified as relating to transition from a care home to a nursing home.

18. Council-funded residents were not aware of FPNC at all.
19. There was some awareness of differences between the funding of services in Scotland and England and some anxiety that things could change quite quickly as a result of political decisions.

Question 2: Are people who need personal and nursing care getting it?

Responses from older people who live in their own home

20. Every group commented on the level of personal care service many people receive, with the main concerns being around bathing and showering not being provided as often as people would like or feel they need. In many cases showering or bathing is limited to once per week. Where people have asked for more help with bathing or showering it has been refused on the grounds of not enough staff. One lady received help with dressing and undressing but only four days per week – on the other days she did not get dressed.
21. Concerns were expressed by over 50 per cent of focus group members about the quality of services provided. These concerns were not about the care staff themselves, but more about the conditions imposed on them and how they have to do their job. There were numerous reports of high staff turnover, not knowing staff when they arrive, being rushed through bathing or dressing, erratic times for getting up and going to bed and having meals. One person reported getting lunch at 2.30pm. Some others reported carers not turning up at all and being left to fend for themselves. There was an overwhelming view that there is not enough staff employed to provide personal care.
22. There were reports of shopping services being arranged in some council areas although these were in the main charged for. There was less evidence of laundry and cleaning services being arranged on behalf of clients. Many of the participants had experienced difficulty finding someone to do cleaning. The rates being charged by commercial companies were stated as being more than the council, and rates of between £10 - £12 per hour were quoted. The cleaners being employed privately appear to be private individuals and not necessarily from any regulated agency or subject to any checks. A number of participants explained that their domestic helps also did some shopping or laundry. A couple have a shower when their cleaner is in the house.
23. With some exceptions personal care packages were provided seven days a week, with support usually being provided more than once a day. The main focus of care was helping people get up, get

washed and dressed; the provision of meals; undressing and putting to bed. No-one mentioned the supervision of medication despite the strong likelihood that many of the participants would be taking medication.

24. Some participants thought there were inconsistencies in how services were allocated within the same council area. This was expressed as questioning why certain people got certain services – probably based more on perception than fact. There was however some evidence that different councils operate different procedures with different ways of assessing priorities. This became apparent when reviewing the notes from all of the focus group and were in the main about availability of post-hospital care; frequency of services like bathing; access to free NHS podiatry; availability of shopping services and laundry; and help finding domestic support.
25. In some areas there appeared to be a lack of clarity around who was responsible for laundry in the event of wetting or soiling. This was of particular concern for people who had a continence problem or a catheter and were living in areas where a laundry service was not provided and laundry was not designated as 'personal care'.
26. Minority ethnic elders were not usually accessing statutory services and were relying on specialist community organisations to provide respite and care at home. There was a very poor understanding of FPNC amongst minority ethnic elders, including what seems to be a belief that FPNC is a stand-alone service which has to be requested.

b. Living in a care home

27. In one care home the staff were unaware of FPNC and no FPNC information had been given directly to residents in any of the homes.
28. Access to dentistry and podiatry was a concern raised in two of the focus groups with most residents having to pay privately for podiatry. This was a particular problem for care home residents.
29. Lack of care staff was again blamed for infrequency of bathing and help with showering.
30. Care home residents were less likely to know about any assessment of need. Where carers were involved they were more likely to know about the assessment than the resident.
31. Around one-third of the care home residents stated they had not been given any choice of care home. One resident reported she had been moved from another home some 18 months ago but she was not consulted about this.

32. In one care home, focus group participants stated that there was little or no contact with social workers, other key workers or advocates regarding care plans, financial discussions or general happiness with the services they were receiving.
33. There were, however, no reports of excessive waiting times – once assessments had been carried out services appear to have been put in place fairly quickly, although there was usually no choice of provider offered. Participants generally felt they had to just accept what they were given.

Question 3: Has the introduction of FPNC made it easier or harder to get other services which older people feel are important

Responses from older people who live in their own home

34. All community-based focus groups reported increased difficulty getting domestic help which they felt was important for health and well-being. There was a general view by participants that social work no longer see domestic help as being their responsibility. Accessing help with laundry was also a fairly widespread problem. One person reported having to send her washing to the local laundry as she could not do it herself and another reported that she dries her washing on radiators as she is no longer able to hang it outside.
35. There appear to be different practices with regard to shopping services and again different charging policies. One participant reported having a choice between cleaning and shopping but she could not have both.
36. Some charging policies were challenged by the majority of groups – particularly charges for community alarms systems and for key safes to allow care staff to access properties. The average costs reported for these are around £4 per week for community alarms and £40 for key safes.
37. In addition many people also paid for window cleaning and those with gardens frequently paid for gardening and lawn cutting.
38. Introducing frozen meals in place of home helps doing some cooking was also criticised by two of the focus groups. Some people reported never having a 'properly cooked' meal anymore.
39. Access to free foot-care appears to differ depending where people live. One lady who had chronic pain and could not bend down was refused a nail cutting service as she was not a priority.

Response from older people living in care homes

40. Care home residents are generally charged for services like hair cutting and styling, toiletries and newspapers. They can also be charged for podiatry. One care home resident reported having more regular bathing because she paid extra.
41. Lack of knowledge about what they are being charged made it difficult for many care home residents to comment on any impact FPNC may have had on charges for additional services.
42. A small number of residents reported a delay in accessing a care home place from hospital. One person had been admitted to another home while waiting for the home of his choice.

Appendix 1.

Quotes from focus group participants

People think that because we are little ladies and we're in little homes that we don't need our houses cleaned. That's ridiculous

Don't know how charges are made up

What about things like toenail cutting?

It used to be nurses that gave them showers – but now its home helps

As far as meals on wheels is concerned, it's changed and getting our feet done has changed.

I am up at 7.20am waiting for my shower

I asked for a cleaner but the council don't do that

I think there's not enough information given out

I have no idea what's being paid for and what's not

I read about it in the paper. I didn't know if I got it

Things such as getting a bath. Do you think it depends on the wealth of an area?

Services are good but have a long way to go

The likes of the council carers, there's a lot of things they're not allowed to do. They're not allowed to go on steps. I don't think they are supposed to iron. You know there's quite a number of things that they don't do

If they're an hour away shopping that's £10.92. That's a lot added onto your shopping

Came straight from hospital after a wee delay

Instructed to move here

Care is not the same as help, is it?

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