

Appendix A: Day services for younger people with dementia

1. Overview

The consultation proposals were included in a letter to everyone currently using the day centre and outreach services. The letter was written by the Commissioning Manager, Dementia, and sent out by the Alzheimers Society Leeds office, who judged whether to send the letter to the person, main carer or both. There were twelve people who asked for a consultation meeting – four who attend the day centre, seven who use the 1:1 outreach provision, and one who uses both services.

This is c. 25% of the total, perhaps reflecting the difficulties people had in sparing time to meet, and / or a lack of confidence that their views would lead to change. This view was evident in some of the consultation responses, which referred to instances of cuts in other services or reported in national and local news; and in two instances, experience of consultations that had led to care homes being closed, and they felt the 'real decisions' had already been made before the consultation.

There were 12 consultation meetings, of which 9 involved the person with dementia and main carer together, and three were with one or more family carers but not the person with dementia. There were two additional meetings: one with a concerned staff member; and one with a former outreach staff member who is now retired, but still very much involved with local dementia-friendly communities, supporting people with dementia and running groups and activities. All of these meetings lasted from 1-1.5 hours and went into some depth eg. about the experience of developing dementia, being diagnosed and the difference that the services had made, as well as the potential impact of the proposed changes.

It had been intended to contact people who don't use the services via the Younger People with Dementia Team (YPwDT), an NHS service provided by Leeds and York Partnerships NHS Foundation Trust. This would not be part of formal consultation on the impact of changes to the day services, but broader conversation about the design of services. However, it was not possible to separate out a mailing list of people who were already diagnosed with dementia, from those who are going through memory assessment, or diagnosed with Mild Cognitive Impairment and kept under review. Instead, the Commissioning Manager, Dementia met with the specialist YPwDT social worker to gain an overview of other services which people use and priorities for improving services..

2. Feedback re. charging policy

- a. *Mr and Mrs A:* Mrs A has vascular dementia, diagnosed five years ago in her early fifties, and her ill-health dates back go back to a head injury suffered in her late thirties. It affects her ability to occupy herself, make safe judgements around the house (she has fallen several times and been hospitalised), and she becomes fixated on subjects, very repetitive and agitated. Her memory for people and names is reasonably good. She has been attending the day centre at Armley Grange for five years and now attends 4 days per week.

He used to work as a public sector employee but after her head injury incident he took time off, decided he needed more flexibility at work, retrained in horticulture and became self-employed. He still works when his wife is at the day centre

(previously he used to take her round in the van with him, which didn't work).

Work is still affected by caring responsibilities, so is part-time and income fairly low. There are occasions when she doesn't want to get in the car to go to the centre or to come home, so he has to break off work to drop her off / pick her up.

His parents died in the 1990s and they invested the inheritance in a second property which is in both their names; this is rented out but Mr A reports only about £1K per annum each of income from it. He doesn't have time to manage the property given the caring role and so some is lost on agent's fees. So they have this asset but not cash savings or high income. This means they would be assessed to pay full cost of care, and have already paid full cost of assessed adaptations to their own home (a shower / wet room). This cost £18K and he reports cashing in his public sector pension to cover this. He says the second property is their only fallback for retirement income, and he's not sure what to do for the best, and just doesn't have the time or energy to get his head around what to do for the best financially. If his van broke down it would be very difficult to afford a replacement and so continue working.

He says that if they had to pay the full cost for day care "I'd just pack up" as he wouldn't earn enough to make it worthwhile. Throughout our conversation, Mr A seemed very tired indeed, and his voice tone was very flat. I was struck by the point about their second property and the difference between having an asset means-tested in later life, compared to when one is still in middle age. If the Council were to apply charging policy, there is a risk that they would give up important services and he'd give up work, ie. both his income and his carer break.

The financial options for them seem quite complex, and her consent to selling the property could also be a complication - the Council might have to let a charging debt accrue against her half of the property. So very personalised steps would be required to mitigate the impact in this case, requiring eg. independent financial advice and reassurance from the Council.

- b. *Mr and Mrs B. / Mr and Mrs C:* both have experience of changes to and complexity of employment and disability benefits: Mr B is carer for Mrs B, and on one occasion claimed for free dental treatment on the basis of receiving Employment Support Allowance. He reports that it turned out that he was on the wrong type of ESA to qualify, and he was interviewed under caution and fined £100. Mr and Mrs C have had problems convincing Atos of his lack of fitness for work, and they were expected to come to York for an assessment. Along with other consultees, they expressed resentment in that they never asked to be in this situation, had lost income as a result, and the requirement to divulge information about finances and 'jump through hoops' was experienced as adding insult to injury. There is a risk of people refusing the assessment and again deciding not to have services they really need as carers, and which help keep them out of care homes.
- c. *Mr D:* One man, who lives with his son and daughter-in-law, is about to have home care charges increased from c. £90 to £240 per calendar month. They were concerned about the additional impact of charging for day care on top of this.

- d. One carer commented that he had given up a £600pw job as an HGV driver, and now received £50pw Carers Allowance; and that without the day centre he could not continue his caring role - his wife would have to live in a residential home which would be expensive for the Council.

3. *Feedback on 1:1 outreach provision:*

Several people and carers noted that the same worker is provided consistently and two people said the Alzheimers Society had changed the worker when the 1:1 relationship wasn't working well, with positive outcome. Two people who had been aggressive in the day centre setting, or decided they didn't want to go, had been offered the alternative of 1:1 support so the carer could still have a break; this had happened quickly and easily with both services being within the same contract. One consultee had short breaks from both the Alzheimers Society and a home care agency, and explained that the Alzheimers Society worker offered a wider choice of activities and better understood how the person needed support with social interaction; they have a tendency to be disinhibited in use of language and others experience this as very rude.

All carers consulted said they would feel confused by the need to choose between agencies had they been provided with a personal budget to spend, and pointed out that caring for someone with dementia can leave very little spare time and energy to dedicate to this. One carer, who already manages a Direct Payment for domiciliary care support, highlighted that the Alzheimers Society are a phone call away if she needed to talk to someone, which does not happen with a Direct Payment. She feels the Direct Payment and the outreach service complement each other, rather than being alternatives.

4. *Feedback on proposal to move day centre from Armley Grange to Springfield:*

One carer commented that it had taken his wife a long time to settle at Armley Grange, so he was worried about her being unsettled again by a move. Another said that continence problems would be difficult to manage on a longer journey. This couple live within 4 miles from Springfield, so the usual journey time would be longer than to Armley Grange, but still usually be less than 15 minutes if the proposed move goes ahead.

Another compared the resale value of Armley Grange, to the value it has to people and carers, as "peanuts"; another emphasised his belief that it was all about "dollars first", both the proposed move from Armley Grange and the proposal to charge people. He came on a visit to view Springfield Day Centre and said that he felt there was less space overall for the service, and expressed the view that no other alternatives were being put forward, just the one that suits the Council.

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Leeds City Council / NHS Leeds Clinical Commissioning Groups