

Report of: Interim Deputy Director, Integrated Commissioning

Report to: Director of Adult Social Services

Date: 15.02.2017

Subject: Day services for younger people with dementia

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Is the decision eligible for Call-In?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: <i>n/a</i>	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

Summary of main issues

1. The current contract covers the provision of a day centre and a community outreach service. It runs from 1st October 2016 – 31st March 2017, with options for two three-month extensions, which would together take the end date to 30th September 2017. Sustaining this important service provision therefore requires the procurement of a new contract from 1st October 2017.
2. This is an opportunity to review the service model, including the day centre accommodation. Proposals for consultation were agreed at Delegated Decision Panel on 3rd June 2016. Consultation has taken place with people who use the Alzheimers Society's day services and family members. This report describes the views expressed about the proposals and the impact of implementing them. Revised recommendations for the future service provision are made, taking account of this feedback.
3. The recent decisions on the Council's in-house provision have given the opportunity to relocate to Springfield Day Centre at Cottingley, which is a purpose-built centre and it is proposed as a new venue for the day centre and office base for the outreach service. This in turn would vacate the site at Armley Grange, in line with the Council's Asset Management Plan.

Recommendations

The Director of Adult Social Services is recommended to approve:

1. That the Council exercises the options available within the existing contract, pursuant to Contract Procedure Rule 21.1, to extend the contract by two further periods of three months each, to continue the provision of the current services from 1st April 2017 until 30th September 2017, with a contract value of £136,250 for the six-month period.

2. The authority to commence a procurement exercise for the provision of the new service for a contract period of five years, with options to extend by a further three years. The value of the contract is £272.5K per annum.
3. The new model of service delivery and change of location of the day centre, noting the outcome of the consultation exercise.
4. To approve the introduction of the local authority's assessment, eligibility and charging policies to the services, noting the outcome of the consultation exercise. However, further consultation is to take place with people who currently use the services after assessments have been carried out, in order to fully understand the impact of introducing the policies.

The Commissioning Manager, Dementia, to be responsible for ensuring the recommendations are implemented.

1 Purpose of this report

- 1.1 The purpose of the report is to seek approval to: take up options to extend the current contract for day services for younger people with dementia to 30th September 2017; procure day services for younger people with dementia to commence on 1st October 2017; apply Council policy for eligibility and charging for adult social care in a way that takes account of and manages adverse impact on those using the services; and for recommendations for the relocation and future service model for day opportunities for younger people with dementia.

2 Background information

- 2.1 Leeds City Council has a contract with the Alzheimers Society to provide day services for younger people with dementia. At present there are two elements to this: a day centre at Armley Grange, and an outreach service. These services support approx. 50 people with dementia at any one time, and this gives valuable breaks and support for family and other carers. The contract has an annual value of £272.5K. £160.5K is contributed by the Council, and £112K is contributed by the three NHS Leeds Clinical Commissioning Groups (CCGs). The day centre funding element is £180.5Kpa, which provides 15 places per day, five days per week, with 25 people currently attending each week. The outreach service funding is £92K, which supports 25 people to each have one half-day session per week of 1:1 support, usually to go out and about.
- 2.2 The Alzheimers Society has offered these day services since 1997, initially supported by the Council via a grant arrangement, and since 2009 under contract. The most recent contract was awarded following a delegated decision on 3rd June 2016¹, and runs until end March 2017 with options for two three-month extensions.
- 2.3 Developing dementia in middle-age is relatively rare – fewer than one in a thousand people aged 30-64 has dementia; therefore the number of people with a dementia aged under 65 reflects this relatively low prevalence. In this age group, there are 165 people with a diagnosis on Leeds GP registers (end December 2016 figure), and estimates suggest there may be a further 40 – 240 who have dementia but are not diagnosed and not known to services². This compares to a total of 50 people using the current outreach and day care services. Looking ahead, the number of people in the population in this age group is likely to be steady in the next 10-20 years. The prevalence of younger-onset

¹ <http://democracy.leeds.gov.uk/mgDecisionDetails.aspx?Id=83568>

² The research into prevalence of dementia gives a relatively wide range of estimates for people aged 30-64 with dementia,

dementia is therefore likely to remain steady, but will depend in part on population health factors, eg. prevalence of Type 2 diabetes and vascular disease.

2.4 Younger adults with dementia experience the condition and its impact in significantly different ways to older people (albeit with a diverse range of personal experience in all age groups). This is the reason for commissioning a dedicated service provision. Specific services for younger people are recommended in the NICE / SCIE guideline for health and social care of people with dementia³. The differences are both clinical and social:

- Younger people have a different profile of types of dementia. In particular, frontal-temporal dementia is more prevalent in younger age groups than among older people. It presents differently to other dementias, with fewer memory problems early on in its progression, and more behavioural disinhibition and mood changes. There are rare, genetically-inherited presentations of Alzheimers Disease which affect adults in late middle-age (eg. as portrayed in the film Still Alice).
- People who develop dementia in middle-age are often in work, and indeed concerns may be first noticed in the workplace, as was the case for several people consulted as part of preparing this report. Carers may themselves give up or reduce paid work, in turn affecting savings and pensions, giving rise to worries about managing in old age. There may have children in higher education, or indeed aged under 18 (the proportion of children born to parents aged over 35 has risen steadily since 1980⁴); or they may take significant responsibility for young grandchildren. Thus the onset of dementia in middle-age can be a particularly catastrophic life event for people, families and friends. Partners / spouses and others find themselves in entirely unexpected caring roles. Carers often speak of a profound sense of loss regarding family life, plans for retirement, and severe effects on family finances.

2.5 The following proposals for consultation were agreed as part of the delegated decision on June 3rd 2016:

- The continuation of structured, building-based day care provision for those younger people living with dementia, as a targeted provision for people who are eg. unsafe or distressed alone at home and / or whose carers need a break (including to stay in paid work). This would require eligible care needs (which could include carer needs) and come under the charging policy for adult social care.
- A preventive service offer, which could be accessed directly and would not come under eligibility or charging policy. This to include the facilitation of peer support, and help with job retention, volunteering, maintaining family roles and social networks, and access to community facilities. This could make use of the building base as a 'meeting place', as well as using a range of other facilities and venues.
- Discontinuing the 'outreach' element of the block contract for provision of 1:1 support, for which a personal budget is proposed as a better approach in future. This would enable people with eligible needs to access an appropriate level of support, rather than a fixed offer of a single half-day session.
- Appropriate steps to manage the impact of introducing eligibility and charging for people and carers already using the service.

This report describes the views expressed in consultation and makes revised proposals, taking into account the feedback received.

³ www.nice.org.uk/guidance/cg42/resources/guidance-dementia-pdf

⁴ www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsbyparentscharacteristicsinenglandandwales/2014

3 Main issues

- 3.1 The age criterion to access the day services has already been 'softened' to avoid moving people on inappropriately based only on date of birth. This has been to the benefit of a small number of people, some of whom met with the Commissioning Manager, Dementia during the consultation. They have benefited from the flexibility to continue with the services. It does not appear to have caused undue pressure on service capacity to date. Equality legislation supports needs-based, rather than age-based criteria.
- 3.2 This main report refers broadly to themes and messages in feedback from the consultation exercise. More detail is given to illustrate and support the themes in Appendix A.
- 3.3 The Council's charging policy was a cause for concern to most consultees. Firstly, it is not possible to assess fully the impact of the policy prior to implementing it and offering financial assessments. People who are already on means-tested benefits were reassured to an extent about charges being affordable, but many are also on disability benefits so would pay some charges. Secondly, people and carers expressed concerns including that they would have to give up the day service; give up paid work; complex financial situations where there are assets that would lead to the full charge being paid, but income is low; and the consequent impact on retirement income and savings for spouse carers. This was compounded by the exhaustion experienced by some carers, giving little time or ability to concentrate on difficult decisions. The feeling was that it is difficult enough to cope with living with and caring for someone with dementia, without the paperwork, intrusion and charging on top. Further detail is given at Appendix A, para 2.
- 3.4 Set against this is the consideration that the Council has a charging policy for adult social care, which is compliant with the Care Act 2014, designed to apply to all who receive social care services, and is based on a financial assessment. There is an appeals process which takes account of exceptional circumstances. Only the individual receiving care is subject to financial assessment and charging, and eg. a spouse carer's share of joint assets is exempt from the assessment (although couples may choose a joint assessment if this would give a better outcome for them).
- 3.5 These responses and considerations inform the revised proposal for further consultation with existing service-users. This would allow assessments to be carried out and decisions to be made in the light of full information about the impact. It would allow time for consideration of the financial assessment, linking people up with appropriate support to make difficult decisions, and adjustment to change. Some carers' references to eg. laundry costs related to continence problems, and the costs of activities, suggests that allowing for disability-related costs will also be a factor.
- 3.6 Applying charging policy will also have an impact on the contract resource, because currently the provider collects a flat fee from people attending the day centre (£5 per day to cover a meal and contribution to transport, adding up to c. £18K pa). In future, charges would accrue to the Council rather than the provider.
- 3.7 Consultees who use the outreach service were articulate in how helpful, flexible and specialised the service is. There was good evidence that the support is tailored to the interests of the person, and that complex needs including psychological and behavioural needs can be met. Examples of this are in Appendix A, para 3. Colleagues in the adult social care – access and care service identify that purchasing domiciliary care where specialist support is required is at a similar cost to the current block contract with the Alzheimers Society; and identifying sufficient capacity with suitable agencies to replace the block contract would be a concern. These colleagues are able to purchase registered domiciliary care for people who need personal care as part of their support, and they see

this as complementing the Alheimers Society provision rather than having the capacity to replace it.

- 3.8 This feedback therefore indicates that maintaining the block purchase arrangement for outreach support is to be preferred. This is a change from the original proposal, which was to replace the block contract with personal budget options. The approach of individual service funds will be explored with the provider to maximise flexibility in how the outreach resource is used.
- 3.9 There were concerns about the proposal to move day centre premises, along the lines of not changing something that's working well, and the potentially disorientating effect. One person with dementia talked about both sides of the decision, in that they were enthusiastic about having better facilities and more different rooms to give a choice of activities; but feeling a little worried about change and appreciating that Armley Grange is an old building with history. Alheimers Society staff, people who attend the day centre and carers have visited the Springfield building to help understand the potential impact of a move, give a further opportunity to identify and manage any risks, and there will be further opportunities if the change of venue is approved. Further information is at Appendix A, para 4.
- 3.10 Set against these concerns are the points that Springfield is purpose built for day care, has previously been the venue for a 30-place day centre (the current younger dementia service is a 15-place centre), has 'break-out' rooms and a small kitchenette that people can use for drinks and snacks, and a bigger outdoor space. Some people visiting the building for the first time were already starting to talk about what could be done indoors and out to make it a good place for them. It is acknowledged that it works for the Council to make use of the Springfield building, as it cannot be sold off, given that the building is shared with a children's service (which is not accessible from the day centre side other than via a corridor which is easily secured). Although the change of building will be disorientating for people, the staff and other people attending will be familiar and there is published evidence that well-managed and supported change can be neutral or beneficial even for people with dementia⁵.
- 3.11 Therefore it is proposed that the premises of the former Springfield Day Centre are specified as the new day centre venue, to enable the service to move from Armley Grange and to offer improved facilities. People using the day centre and carers to be offered the opportunity be involved in plans to develop and move to the premises. The Springfield day centre building would require redecoration and other improvements to be fully suitable, including consideration of dementia-friendly environment, use of the available spaces, and layout. Discussions will take place between the service provider, Adult Social Care and City Development officers regarding improvements and funding for this. It is proposed that a contribution to redecoration and removal costs would be affordable when set against the potential capital receipt from Armley Grange.
- 3.12 There was no specific comment on eligibility criteria, perhaps because it is difficult for people who have not been through the assessment process to understand and comment. There was general concern from experience of having to deal with paperwork and prove eligibility for benefits, which suggested that the assessment process must be handled sensitively. However, there is evidence to suggest that the assessment process can be a factor in improving lives for people going through service changes (see reference at footnote ⁵). Therefore, it is proposed that new referrals for these day services (ie. day centre attendance and one-to-one outreach) are subject to the Council's current assessment and eligibility policy under the Care Act 2014. Assessment of fifty existing service-users would be a logistical challenge in a short time scale, therefore it is proposed

⁵ <http://www.birmingham.ac.uk/news/latest/2012/05/25-May-Care-Home-Closures-News-Releases.aspx>

to assess the needs of people currently using the services and carers and take account of any adverse impact in implementing any changes to service level.

- 3.13 To complement the day care and outreach provision, it is planned to develop a 'preventive' service offer within the new specification as far as possible within the available resource, which will not be subject to assessment, eligibility and charging. This would complement what is already available from eg. the Council's Dementia Peer Support Service, the Younger People with Dementia Team (NHS service), and the Memory Support Worker Service (Alzheimers Society / NHS). The priorities identified are carer support (including peer support), improved signposting to other services (eg. carers emergency plan), and seeking increased involvement from volunteers to enhance provision.
- 3.14 The provision of transport currently costs c. £30K of the £180K resource for the day centre. This is provided by the Alzheimers Society directly, via paid staff using two vehicles owned by the Society, and two volunteer drivers using their own cars and paid mileage. Transport is provided from all around the Leeds area, distances of up to 15 miles. The provider has explained that they would prefer to focus on their role as a care service provider and not be subject to the risks from transport provision, given the heavy reliance on volunteering and the lack of options if there is vehicle breakdown or driver illness. They report that their information from Leeds Alternative Travel is that providing an equivalent service with full ownership of risks and contingencies would cost £46K. The options for transport include:
- Accepting the additional cost within the contract resource, with less resource available for service delivery;
 - Explore possible solutions with the Council's transport service, which may have capacity with the reduction in day care provision;
 - Continue to accept the risks of transport arrangements where contingency plans are less robust; this may not be an option if providers choose not to bid for the contract in these conditions, a step which the Alzheimers Society would consider.
 - As part of a solution, promoting independent travel where possible (likely to be limited) and requiring Access and Care to resource transport needs (with consequent impact on budget).
- 3.15 A period of five years is proposed for the contract duration, with options to extend for a further three years, because the need for the services is well-established and the risk of purchasing a service that is under-utilised in future appears to be very low.

4. Corporate Considerations

4.1. Consultation and Engagement

- 4.1.1. During the preparation for the 2011 procurement exercise there was substantial consultation with both service users and carers. This was used to inform the service model and service specifications and demonstrated the need for these services. Since then, service user views are sought as part of the on-going contract monitoring and service users and carers have told us how much they value the services.
- 4.1.2. A small workshop was held at Armley Grange on 10th July 2014, with people who attend the day centre, carers, a person with dementia and staff from the Leeds Dementia Peer Support Service, and Alzheimers Society staff. There was further expression of support for the service as it is by existing service-users and carers. The person who attends peer support activities, but not day care, found it hard to think about what might happen with the

progress of their dementia; it is perhaps a 'coping strategy' to live each day at a time and not look too far ahead.

- 4.1.3. A provider engagement event was held on 23rd April 2015, attended by representatives of 10 providers. This demonstrated a real enthusiasm and confidence for developing day opportunities and making use of community resources, and commissioning officers are expecting a higher level of interest than experienced in 2011 in providing this service.
- 4.1.4. There was consultation, as described above and at Appendix A, on the proposals agreed as part of the Delegated Decision on 3rd June 2016. The consultation proposals were included in a letter to everyone currently using the day centre and outreach services. 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.
- 4.1.5. 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. 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.
- 4.1.6. 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. 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. Therefore this has not yet been pursued, as the priority has been to understand the impact of the proposed changes on the people already using the services.
- 4.1.7. The Commissioning Manager, Dementia has met with the specialist YPwDT social worker to gain an overview of needs of, and services used by people who do not use the Alzheimers Society's services. If authority to procure is agreed, then further steps to understand the wider population of younger people with dementia and carers will be considered in developing the service specification.

4.2. Equality and Diversity / Cohesion and Integration

- 4.2.1. The Equality, Diversity, Cohesion and Integration screening form has been completed, and is attached as Appendix B. This confirms that the decision on the future of day opportunities for younger people with dementia have potential impact, both beneficial and adverse, on people with protected characteristics under equality legislation. This includes people living with dementia (as a disabling condition); consideration of age quality; and ensuring services can meet the diversity of need within these groups. These aspects have been explored through the consultation process.
- 4.2.2. The decision on the recommendation to change the day centre venue must take into account that people with dementia are less able to learn new environments and more at risk of becoming disoriented and confused. It is recommended that these considerations are balanced by the availability of skilled staff to support the transition, the suitability of the proposed new venue and the planned development of a dementia-friendly environment.
- 4.2.3. The recommendation to continue with the purchase of 1:1 outreach support acknowledges the views expressed in consultation regarding the importance of relationships and continuity for people living with dementia, and providing tailored activities as well as carer breaks. The

capacity of the existing service is important, to support people whose psychological and behavioural needs are more advanced, with risks of aggression to staff.

4.2.4. It is anticipated that the Leeds population with dementia will become gradually more diverse in its black and minority ethnic (BME) composition. This is because the population of Leeds, in common with other ethnically-diverse cities, has a higher proportion of children and young adults who identify as 'black and minority ethnic' (BME), and, over time, this will work its way through to later middle-aged and older age groups. Dementia prevalence may be higher in BME communities compared to the majority ethnic "white UK" population, given the known higher prevalence of Type 2 diabetes in south Asian and Caribbean communities, and the evidence which associates this with higher prevalence of both Alzheimers Disease and vascular dementia. Two of the people participating in the consultation process referred to a diagnosis of vascular dementia.

4.2.5. Officers have noted progress made by the current provider in catering for emerging diversity of people with dementia, and offering a wider range of activities. Although the recommendation is to continue with the purchase of similar services from October 2017, the need to support an increasingly diverse population with dementia will be reflected in the service specification.

4.3. Council policies and Best Council Plan

4.3.1. The Best Council Plan (2016-17 priorities) includes:

- Building capacity for individuals to withstand or recover from illness. It is hoped to support people better to live with dementia, by engaging people and families / carers, to co-design the service and broaden the range of support available
- Enabling carers to continue their caring role and careers. The current service contributes to this aim especially by providing carer breaks for day care. It is hoped to sustain this, whilst offering more options for people not suited to day care.

4.3.2. The commissioning of these services is in line with the vision and priorities outlined in the Leeds Dementia Strategy. A service model which supports people to be a part of the community and get 'out and about' fits with the aspiration to become a dementia-friendly city.

4.4. Resources and value for money

4.4.1. The annual contract value and breakdown is shown below.

NHS contribution	£112K
Local authority contribution (equal to current cost of the day centre at Armley Grange)	£160.5K
Total	£272.5K

4.4.2. NHS funding is allocated through a s256 agreement made originally with the (then) NHS Leeds Primary Care Trust, which is now held by NHS Leeds North Clinical Commissioning Group. The NHS contribution is now part of the Better Care Fund.

4.4.3. Cash efficiencies of 5% were made within the contract in both 2011-12 and 2012-13. The provider has moved from offering hot meals to 'sandwich-and-soup' type midday meals. Savings have not been pursued further because of transport costs that the provider has not

been able to reduce, commissioners' appreciation of the level of volunteer support, and concerns about sustainability.

- 4.4.4. A further saving of £20K has been made from October 2016, as described in the Delegated Decision of 3rd June 2016. This is because the post of Dementia Advisor duplicated the role of the Memory Support Worker service which has been commissioned by the local NHS, and so this post has been removed from the contract.
- 4.4.5. The Council would benefit from the opportunity of a vacated site at Armley Grange, potentially for sale for development; ie. there is an "opportunity cost" associated with continuing with a day care service at Armley Grange. There are also maintenance costs for the building.
- 4.4.6. The contract from 1st October 2017 requires an estimated budget similar to the current contract funding, but taking into account possible changes in premises cost, transport and catering; and the impact of applying charging policy on the provider's income. Further work is required to develop the service specification and pricing schedule to resolve important practical and resourcing issues, including: the specification for transport provision; provision of meals at the day centre; the market rental assessment from Asset Management colleagues; and the nature of the agreement to use the day centre premises linked to the contract.

4.5. Legal Implications, Access to Information and Call In

- 4.5.1. This report is listed as a key decision and has been published in the Forthcoming List of Key Decisions for 28 days, because of the annual values of the contracts, and is therefore subject to the call in procedure.
- 4.5.2. If authority to procure the service is agreed, the decision to award a contract will be a Significant Operational Decision and will therefore not be subject to call-in.
- 4.5.3. Meaningful consultation is required when considering the impact of service changes, and to policy decisions, including potential impact affecting the groups defined in equalities legislation. People with dementia are, by definition, people with disabilities, and carers must also be considered within this 'equality strand'. This report describes the changes made to the original proposals as a result of consultation, having taken account of the views expressed in the consultation meetings, and balanced these with other considerations.

4.6. Risk Management

- 4.6.1. Changes to current provision and charging present risks to the well-being of the people already supported by the current service model, and a risk to the Council's reputation. A consultation process is described which has identified potential adverse impacts and makes proposals for how they will be managed.
- 4.6.2. A five-year contract period with options to extend for a further three years would ensure stability for the provider and people using the services, with very low risk to the Council that the service would be under-utilised, given the long period of high occupancy that the day centre has achieved, and the unsolicited positive feedback in consultation about the value of the day centre to people with dementia and carers.

5 Conclusions

- 5.1 The future service provision of day services for younger people with dementia is important to sustain highly-valued provision of meaningful activity and carer breaks to people using

the services now, and develop it for people who will need support in the future. This report attempts to balance the case for change against the impact

6 Recommendations

The Director of Adult Social Services is recommended to approve:

- 6.1 That the Council exercises the options available within the existing contract, pursuant to Contract Procedure Rule 21.1, to extend the contract by two further periods of three months each, to continue the provision of the current services from 1st April 2017 until 30th September 2017, with a contract value of £136,250 for the six-month period.
- 6.2 The authority to commence a procurement exercise for the provision of the new service for a contract period of five years, with options to extend by a further three years. The value of the contract is £272.5K per annum.
- 6.3 The new model of service delivery and change of location of the day centre, noting the outcome of the consultation exercise.
- 6.4 To approve the introduction of the local authority's charging regime to the service, noting the outcome of the consultation exercise. However, further consultation is to take place with people who currently use the services after charging assessments have been carried out, in order to fully understand the impact of introducing the policy.

The Commissioning Manager, Dementia, to be responsible for ensuring the recommendations are implemented.

7 Background documents:

- 7.1 NONE