

Report of: Interim Chief Officer, Commissioning, Adult Social Care

Report to: Director of Adult Social Services

Date: 1st June 2016

Subject: To approve the proposals in connection with the future of day opportunities for younger people with dementia

Are specific electoral Wards affected?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
If relevant, name(s) of Ward(s): Armley. The services discussed are city-wide, but the report proposes a change of service location from Armley Grange.		
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 type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If relevant, Access to Information Procedure Rule number: Appendix number:		

Summary of main issues

1. Leeds City Council has a contract with the Alzheimers Society to provide two services for younger people with dementia: a day centre at Armley Grange, and an outreach service. These services support approx. 50 people with dementia, plus family and carers. The services are generally used to full capacity, and well-regarded. There are opportunities to improve provision by reaching more younger people living with dementia; offering more choice and access to community life and facilities; and bridging the gap between the traditional 'cut-off' at age 66, which is very young to transition to older people's services.
2. The contract has an annual value of £292.5K. £180.5K is contributed by the Council, which equates to the funding of the day centre, which provides 15 places per day, five days per week, with 25 people currently attending each week. £112K is contributed by the three local NHS Clinical Commissioning Groups, which equals the outreach service funding. This currently supports 25 people to each have one half-day session per week of 1:1 support, usually to go out and about; and funds a Dementia Advisor post.
3. The Alzheimers Society now (since October 2015) employs a team of Memory Support Workers (13 full-time equivalents), funded by local NHS commissioners and under a sub-contract with Leeds and York Partnerships NHS Foundation Trust. These new roles include the provision of post-diagnosis information and advice. Therefore the need for the Dementia Advisor post can be reconsidered in the light of this development.

4. The current contract runs from 1st October 2014 – 30th September 2016 and this aligns with the expiry of the Alzheimers Society's lease agreement with the Council at Armley Grange. Their Leeds office and day centre occupy the main building on the site, a grade II listed building dating from the early 19th century.
5. City Development colleagues propose that the Council should reclaim the site at Armley Grange for potential alternative use or sale. Leeds Centre for Integrated Living (CIL) also has office accommodation on the site in a low-rise concrete building, where there are concerns about the floor structure. They are being supported to identify new premises. Leeds Disability Information and Advice Line (DIAL) has already been supported to move from this building.
6. The Council therefore has to make decisions regarding service provision for younger people with dementia, after the end of the current contract, ie. from 1st October 2016. The issues include: the nature of the service; the relatively small size of the population cohort with younger-onset dementia; the definition of "younger people with dementia" with regard to equality legislation; assessment, eligibility and charging; and the overall contract resource which currently includes a below-commercial-cost lease at Armley Grange. The final decision must take account a range of factors, including the wishes of people and carers currently using the services; and the impact of any changes.
7. The day centre and outreach services are very much appreciated by people who use them, and families / carers. However, it is important to consider the needs of people who do not use the services, and whether offering more opportunities and options, could increase the number of people who access support to live with dementia. These could include access to the community, sustaining and seeking employment and volunteering roles, sustaining family roles, and support to access individual budgets and plan support.
8. There is no requirement at present for people who access these services to meet eligibility criteria or to pay charges. This simplifies access to the services, but is not consistent with practice for day services for other vulnerable people; therefore equity is an issue. It also means that the important step of a community care assessment can be missed out. People living with dementia and carers should be supported with the offer of assessment and care planning, which takes a holistic approach to people's strengths and needs, and considers alternative ways of achieving outcomes.
9. Non-renewal of the lease at Armley Grange would have a potential impact on the ability of the Alzheimers Society to maintain a Leeds office, and thereby operate effectively both as a local partner for the Leeds dementia strategy; and as a point of contact for people living with, or worried about, dementia. The Alzheimers Society offer this helpful service, which is publicised by the NHS locally and the Council, from their own resources. It is in part enabled by the lease conditions with the Council, but is not provided under contract. Although this is a separate matter to the day centre provision, it is important to consider this local presence and its value to Leeds citizens, in the impact of any decisions about Armley Grange.

Recommendations

The Director of Adult Social Services is recommended to approve:

1. The waiver of Contracts Procedure Rules 9.1 and 9.2 using the authority set out in CPR 1.3, to enter into a contract with the Alzheimers Society for the provision of a day opportunities and an outreach service for younger people with dementia. The duration of this contract is proposed as 6 months from 1st October 2016 - 30th March 2017; with options for two three-month extensions, potentially taking the

contract to 30th September 2017. The contract has an annual value of £292,500, of which £180,500 is Council funding, with the addition of £112,000 transferred to the Council via a s256 agreement from NHS. Provisions are available within the agreed budgets.

2. That Leeds City Council commences engagement with younger people with dementia, families & carers and other partners on an outline proposal for the future of specific services for younger people with dementia. This should seek to 'co-design' a service specification for future procurement of day services for younger people with dementia, and understand the impact of proposed changes from the current services. Following this exercise, a further report should be prepared with recommendations for the procurement of services and managing the impact of any changes to current provision.
3. The outline service model, to be proposed for engagement and co-design, to be based upon:
 - a. 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.
 - b. 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.
 - c. 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.
 - d. Appropriate steps to manage the impact of introducing eligibility and charging for people and carers already using the service.
4. That the £20K element of the contract funding which supports the Dementia Advisor post is removed from the new contract, and the provision of a Dementia Advisor is thereby decommissioned, noting that the Memory Support Worker service is now in place.
5. That discussions continue with the Alzheimers Society regarding the future location of their Leeds office. Consideration should be given to measures to enable the Society to maintain its base in Leeds, ideally at a location which is well-known and accessible.
6. The Integrated Commissioning and Transformation Manager (Dementia) is responsible for ensuring that these recommendations are implemented, and that the service design and procurement process is completed within the timescales referred to above.

1 Purpose of this report

- 1.1 The purpose of the report is to explore the options for the future of day opportunities for younger people with dementia; including the future of the current building at Armley Grange. This includes balancing proposals for change and

intended benefits for people who may use the service in future; with the potential impact of any changes on people and carers who are using the services now.

2 Background information

- 2.2 The Alheimers Society has been delivering these services since 2009 under contract. The day service has existed since 1997, supported by the Council via a grant arrangement. The day centre at Armley Grange is funded at £180,500, which equals the Council's funding contribution. The outreach service is funded at £112,000pa., which corresponds to the contribution from NHS Leeds Clinical Commissioning Groups. The current annual contract value is therefore £292,500. There are quarterly meetings to monitor the service and manage the contract. Initial engagement with people who attend the centre and carers indicated that they are very happy with the service and there were comments to the effect that it's a 'lifeline'.
- 2.3 The adult social care commissioning team have carried out initial exploration of options for the future of the service. The following options have been considered and judged *not* to be suitable for the future of these services:
- a. Ceasing to offer day services from a building base. This would lose the benefit of bringing people together for mutual support. It would make it very difficult to meet some people's needs for a safe environment with a degree of 'watching over'. It would be a difficult transition to manage without affecting people using the service now.
 - b. Moving to a 'hub' model with the younger people's services sharing buildings with day care for older people with dementia: The younger and older people's groups have differing needs, and the buildings are not well-designed to be partitioned or shared. It had been hoped that this would lead to savings in transport costs and reduced journey times, but actually the need for multiple pick-ups / drop-offs negates this, even if distances 'as the crow flies' are shorter. The older people's day centres might, however, offer an option for younger adults with physical and personal care needs.
 - c. A further option for a locality model, sharing accommodation with mental health hubs: the hubs have very good facilities for activities, but the need to allow easy coming and going would not be compatible with the needs of some younger people with dementia. These hubs could make good meeting places and bases for some activities.
- 2.4 The proposed continuation of a building-based service leads to a requirement to identify a building suitable as a day centre. Among the options could be buildings which are used for older people's day care and currently subject to consultation and decision-making. This consideration leads to a requirement for flexibility in the timescales for decisions regarding these younger people's services, in order to allow the options for available buildings to become clearer.
- 2.5 Council officer colleagues in City Development (Asset Management) indicated during 2013 that the Alheimers Society lease on the building was coming to an end on 30th September 2016. A report to Delegated Decision Panel on 3rd April 2014 proposed that the contract for the day service should be aligned to the end of this lease. This was in order to avoid going out to procurement with the complication of one potential provider having a lease with the Council which would

expire during the contract term. The Director of Adult Social Services agreed to a request to "waive Contracts Procedure Rules 9.1 and 9.2, using the authority set out in CPR 1.3, to enter into a 2 year contract for dementia services provided by the Alzheimer's Society from 1st October 2014 – 30th September 2016". The reason for extending the timescale further has been the consideration of options which depend on the decisions made regarding the future of in-house provision of services for older people.

- 2.6 A provider engagement event on 23rd April 2015 indicated stronger potential interest in a procurement process compared to 2010-11, including different organisations working in partnership, and a positive attitude towards more community-based options and opportunities.
- 2.7 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 incidence. In this age group, there are 161 people with a diagnosis on Leeds GP registers (end March 2016 figure), and population prevalence estimates suggest there may be a further 40 – 240 who have dementia but are not diagnosed and not 'known' to services¹. This compares to a total of 50 people using the current outreach and day care services. Looking ahead, these numbers are likely to be steady in the next 10-20 years. This is a contrast to the expected increase in numbers of older people with dementia, which are increasing in line with the increase in the numbers of people aged 75+.
- 2.8 Younger people 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. Younger people with dementia are often in work, 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 1980²); 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. . However, we do know that the right support and services can help people to cope better with dementia, and for some people even to say that they are "living well".
- 2.9 Younger people also 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*). Specific services for younger people are recommended in the NICE / SCIE guideline for health and social care of people with dementia³.

¹ The research into prevalence of dementia gives a relatively wide range of estimates for people aged 30-64 with dementia,

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

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

- 3 Main issues** Equality legislation and the lack of alternatives for people aged 65-69 support the view that a strict age cut-off, though it has been a feature of younger dementia services, should no longer be applied. Instead, a needs-based definition will be required, describing whom the service is intended for, with more flexibility regarding age. The impact of broadening the age criteria is likely to be an increase in the number of people referred to the service, or remaining within it. There are an estimated 550-600 people aged 65-69 living with dementia in Leeds, of whom c.400 have a diagnosis.
- 3.2 There is potential to offer more opportunities for meaningful activity. Over the past 5 years, commissioners have developed the specification for the day centre and outreach services, and the Alzheimers Society has worked to develop the service itself. There are more activities taking place, eg. a walking group, and working with LYPFT staff to run cognitive stimulation therapy sessions. This progress should be continued, both by developing more community options, and more activities within building-based day care.
- 3.3 Since 2010, the Leeds Dementia Peer Support Service has been piloted and sustained, and proved very successful at using community facilities and working with partners (Leeds United Foundation, Leeds Museums and Galleries, West Yorkshire Playhouse) to offer a range of opportunities and therapeutic activity. Peer Support does not provide transport, so relies on people being able to travel independently or have help to get to groups and activities. The Council should learn from the success of this peer support and partnership model, and attempt to offer a wider range of opportunities to people who need more support to access them.
- 3.4 The outreach service within the current contract provides 1:1 support to access the community, which by its nature, serves a relatively small number of people (25) for only half a day per week. An alternative approach, already used by a small number of people in Leeds, would be to purchase support via a direct payment or individual service fund. This would enable the level of support to change according to assessed needs.

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. Some engagement has already taken place with relevant stakeholders in order to inform future service provision. This included a small workshop with people who attend the day centre, carers, a member and staff from the Peer Support Service, and Alzheimers Society staff, at Armley Grange on 10th July 2014. There was further expression of support for the service as it is by existing service-users and carers. To date, it has been found that people in the earlier stages of dementia find it hard to think about needing a different level of service as the dementia progresses; it can be a 'coping strategy' not to 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. However, the potential impact of change, in particular any withdrawal of the service at the Armley Grange building, indicates that further engagement is required. This would give commissioners feedback on the proposed model and the opportunity to change it in response; and would enable the Council to understand, manage and mitigate any adverse impact.

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 an Appendix. 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 equality; and ensuring services can meet the diversity of need within these groups. It is proposed to explore and understand these through a consultation process.

- 4.2.2. 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.

- 4.2.3. It is proposed that a more personalised service model which accesses community resources, can cater for a diverse population more successfully than a traditional day centre. Throughout the current contract the provider has worked hard to make the service more accessible to diverse community groups and this will continue to be a priority.

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 socially-included 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. The outreach service funding also covers the cost of a 'dementia advisor' full-time equivalent post (£20K pa.) which is not directly part of the outreach service itself, but was mutually agreed through the contract management process. The dementia advisor role will no longer be required in a new contract, because the new Memory Support Worker service is providing post-diagnosis information, advice and support.

NHS contribution (equal to current cost of outreach service, plus dementia advisor post).	£112K
Local authority contribution (equal to current cost of the day centre at Armley Grange)	£180.5K
Total	£292.5K

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. The unit cost of day care per place per day is £46. For the outreach service, unit cost is £71 based on 25 sessions per week (maximum available), and subtracting the cost of the Dementia Advisor post from the contract value.

4.4.4. 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.

4.4.5. The Dementia Adviser element of the contract now duplicates the role of the new Memory Support Worker service. Therefore £20K can be saved compared to current expenditure, by decommissioning the provision of a Dementia Adviser. Discussions with the Alzheimers Society would seek to manage the impact of this by planning the transfer of the work of the Dementia Adviser to the Memory Support Workers (MSWs).

4.4.6. Additional demand on the service would be created by increasing the age range beyond the cut-off at age 66. This has been trialled by the provider in consultation with commissioners, and is currently being managed within the existing resource, but it is reported that this has reduced the capacity to offer places for new people. The numbers of people with dementia up to age 70 would more than double the potential demand.

4.4.7. The Council could benefit from the opportunity of a vacated site at Armley Grange, either via alternative use, or sale; ie. there is an "opportunity cost" associated with continuing with a day care service at Armley Grange. City Development colleagues have commissioned a site valuation.

4.4.8. The initial six-month period of the contract which is proposed under a waiver of CPRs, would run to end March 2017. This would align with plans for the Leeds Centre of Integrated Living to move from the site, and would not affect potential capital receipts in 2017-18. However, if the timescales require one or both options to be taken for extension, this would potentially take the lease at Armley Grange to end September 2017 and therefore affect capital receipts in the next financial year.

The Executive Manager for Strategic Asset Management has been consulted on this aspect, and there is understanding of the reasons for the flexibility of timescale, that: A move from Armley Grange would require an alternative location to be identified; and that potentially suitable sites might include buildings where there is dependency on Council decisions regarding in-house provision for older people. The Executive Manager for Strategic Asset Management and the Integrated Commissioning and Transformation Manager, Dementia, are arranging a site visit to Armley Grange in the near future.

4.5. Legal Implications, Access to Information and Call In

4.5.1. This report proposes a significant operational decision, in that the current annual contract value is £292,500, and the recommendation is for a new six-month contract on these terms. However, if taking up the second three-month extension were to be proposed, then this would be a Key Decision, taking the total value over £250K.

4.5.2. Decisions affecting the well-being of people with dementia have significance beyond contract value. However, because this report proposes engagement with people and carers regarding future decisions, it is not yet at the stage of making a key decision.

4.5.3. The legal framework requires meaningful consultation when considering the impact of service changes, and to policy decisions 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'.

4.6. Risk Management

4.6.1. A change to a more personalised service, offering a diverse range of support with employment, financial and family issues, is considered beneficial to younger people living with dementia in Leeds. However, there is a risk 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 would enable risks to be identified and avoided or reduced, and a transition plan will promote person-centred planning of changes.

5 Conclusions

5.1 Although this service supports a relatively small number of people and it is not among the largest contracts awarded by adult social care, there are important issues to consider. It is proposed that the recommendations form a way forward to redesign and reprocure day opportunities for younger people with dementia. However, the timescales required to consult on these proposals, and co-ordinate with proposed changes to local authority day care provision, are likely to require a further extension to the existing contract, and the existing lease arrangement, with the Alzheimers Society.

6 Recommendations

The Director of Adult Social Services is recommended to approve:

6.1 The waiver of Contracts Procedure Rules 9.1 and 9.2 using the authority set out in CPR 1.3, to enter into a contract with the Alzheimers Society for the provision of a day opportunities and an outreach service for younger people with dementia. The

duration of this contract is proposed as 6 months from 1st October 2016 - 30th March 2017; with options for two three-month extensions, potentially taking the contract to 30th September 2017. The contract has an annual value of £292,500, of which £180,500 is Council funding, with the addition of £112,000 transferred to the Council via a s256 agreement from NHS. Provisions are available within the agreed budgets.

- 6.2 That Leeds City Council commences engagement with younger people with dementia, families & carers and other partners on an outline proposal for the future of specific services for younger people with dementia. This should seek to 'co-design' a service specification for future procurement of day services for younger people with dementia, and understand the impact of proposed changes from the current services. Following this exercise, a further report should be prepared with recommendations for the procurement of services and managing the impact of any changes to current provision.
- 6.3 The outline service model, to be proposed for engagement and co-design, to be based upon:
 - a. 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.
 - b. 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.
 - c. 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.
 - d. Appropriate steps to manage the impact of introducing eligibility and charging for people and carers already using the service.
- 6.4 That the £20K element of the contract funding which supports the Dementia Advisor post is removed from the new contract, and the provision of a Dementia Advisor is thereby decommissioned, noting that the Memory Support Worker service is now in place.
- 6.5 That discussions continue with the Alzheimers Society regarding the future location of their Leeds office. Consideration should be given to measures to enable the Society to maintain its base in Leeds, ideally at a location which is well-known and accessible.
- 6.6 The Integrated Commissioning and Transformation Manager (Dementia) is responsible for ensuring that these recommendations are implemented, and that the service design and procurement process is completed within the timescales referred to above.

7 Background documents⁴

7.1 None

⁴ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.