

Dear Councillor,

On behalf of the care team at East Kilbride & District Dementia Carers Group (EKDDCG), our Service Users, and our Carers Support Group, may I respectfully request that prior to you making a final decision on the proposal to terminate our contract for dementia care provision with South Lanarkshire Council, you give consideration to the following facts.

Over recent years, South Lanarkshire Council, in spite of compelling evidence from recognised authorities on Dementia care, has continued their practice of reducing Dementia daycare places in East Kilbride.

Dementia – The Statistics

The Scale of the Problem

It is estimated that there are between **58,000** and 65,000 people in Scotland with dementia, and that the figure will rise to between **102,000** and 114,000 by 2031.

(Source, Alzheimer's Scotland conference, June 2007)

In total, an estimated **700,000** people in the UK have dementia. There will be over **one million** people with dementia in the UK by 2025. *(Source, Alzheimer's Society)*

Official figures projected that within South Lanarkshire, the number of people with dementia would increase over a 10 year period by **25%**. Over that *same period*, the figure for East Kilbride was not 25%, but an estimated at **51%**. *(source, SLC Joint Community Care Plan)*

The 'Experts' View on How To Tackle The Problem

In April 2008, a Ministerial statement on dementia by **Shona Robison MSP** confirmed that the Scottish Government recognises the scale of the problem of dementia in Scotland, as highlighted by the Alzheimers Scotland report "The Dementia Epidemic - where Scotland is now and the challenge ahead." She affirmed the Scottish Government's commitment to '**Make Dementia a National Priority**'.

The following quotes are taken from the Alzheimers Scotland publication "*Meeting Our Needs? – the level and quality of dementia support services in Scotland*", which was published in June 2008.

4 Study findings

- 4.2 Most councils had a waiting list for day care... (Page 3)
- 4.3 Specialist dementia day care was valued by people with dementia, carers and social work care managers alike. However, there is a shortfall in day care provision appropriate to the needs of people with dementia in the majority of councils. (Page 3)
- 4.4 There is a lack of alternatives to day care for people with dementia and an over-reliance on traditional models of day care. (Page 3)

5 Conclusions and recommendations

- 5.1 This study has demonstrated serious deficiencies in the provision of core community care services for people with dementia. It is essential that steps are taken now to relieve the pressure on services and plan for the future increase in the number of people with dementia. (Page 3)
- 5.2 Recommendation: Increased provision of specialist dementia day care and development of the level and quality of day opportunities available for people with dementia. (Page 4)

Dementia – The Statistics (cont.)

The ‘Experts’ View on How To Tackle The Problem (cont.)

3.3 Day care

Health Department Letter (2004) 44 sets no specific targets for day care, so it is difficult to know what level of under-provision this indicates. However, if the highest level of existing provision in Glasgow is used as a target for all councils, this would mean 64% of those needing day care were not receiving it in 2006. (Page 11)

4 Study findings

Specialist dementia day care was valued by social work care managers. However, there is a shortfall in provision and a lack of alternatives to traditional models. (Page 14)

4.4.2 Appropriateness

Many care managers said that specialist provision in their area provided appropriate activities and catered well for the different stages of the illness. However, some felt there was an over-reliance on traditional models of day care, with lack of suitable alternatives. People with dementia had to fit the service available rather than services being suited to their needs. The Care Commission has highlighted the need for improvements in person-centered planning in day care setting. (Page 17)

4.5 Day opportunities

Not everyone will be suited to a group environment; some people with dementia will not enjoy day care and it is important that there are alternatives. Day opportunities are activities that provide stimulation for the person with dementia. They can be individual or group activities, for example support to participate in leisure activities or walking groups. In our survey of people with dementia, 17% of people did not want to attend day care. The importance of stimulation for people with dementia who did not want to attend day care was apparent from carers’ responses. *“My husband would benefit from support to enable him to go out and do activities such as bowling; he does not require actual day care but would love access to social activities and men’s company.”* – Wife of person with dementia (Page 18)

5.1 Recommendations

- Increased provision of specialist dementia day care and development of the level and quality of day opportunities available for people with dementia.
- Clear consistent council eligibility criteria for community care services that provide understanding of how decisions are reached and ensure people with dementia receive the same level of service, in accordance with their assessed needs, wherever they live in Scotland.
- A consistent standard of dementia-specific data collected at council level in a uniform format that enables accurate national statistics to be produced. This is essential for achieving effective strategic planning by providing an accurate picture of provision in each area and enabling analysis of the level of unmet need. (Page 27)

The 'Experts' View on How To Tackle The Problem (cont.)

Harry Stevenson, Executive Director, Social Work Resources, South Lanarkshire Council, was part of a team that worked on the Scottish Governments '**Changing Lives**' review of Social Work.

<https://www.scotland.gov.uk:443/Topics/People/Social-Work-Services/intro>

Changing Lives, the report of the independent 21st Century Social Work Review Group, delivered three main messages and challenges.

- Social work services don't have all the answers, so there needs to be capacity to deliver personalised services
- Best use of social work skills is not made, so there needs to be capacity to develop the workforce
- Doing more of the same won't work, so there needs to be capacity to create sustainable change

These challenges reflect the wider principles of public service reform, placing social work at the forefront of that agenda

- Transformed public services will be organised around individual's needs and legitimate aspirations to help people achieve their full potential as active citizens
- They will drive up quality and innovation and be efficient, productive and focused on outcomes
- **They will be joined up, working increasingly in partnership with others**
- **They will be accountable to those they serve**

The Reality In East Kilbride

The decision of the Council with regards to EKDDCG, supported by Harry Stevenson, is in direct opposition to the very proposals that Mr. Stevenson himself supported as the way forward for Social Work. As for 'accountability'... .. we have consulted our Service Users and Carers. When asked if they would do the same, the Council replied: ***"There will be no consultation with service users and carers until the proposed saving is approved by the Council"***.

There are currently TWO day care centres in East Kilbride which are specifically for people with dementia: The Saltire Centre and the EK Dementia Carers Group in Pine Crescent.

Between them, they provide a maximum of 120 day care places per week (84 at Saltire and 36 at Pine).

Both centres currently have a waiting list. Both centres currently have people attending who have requested increased days, but which cannot be provided due to the excessive demand on both services.

With the closure of Old Coach Road Day care centre and the dementia unit at Claremont home, there are now **less** day care places available in East Kilbride for people with dementia than when the Council forecast a 51% increase in the numbers of people with dementia.

Despite this, purely on an inaccurate financial proposal, the dementia day care provision in East Kilbride would be **reduced by a further 30%** if the Efficiency Savings plan is implemented!

If, however, the Council decide to use one of there existing centres for additional dementia daycare, there will effectively be a cut in daycare services to other Service User Groups to accommodate it.

Group Background

- East Kilbride & District Dementia Carers Group is a daycare support service for people with dementia.
- EKDDCG is registered with the Care Commission
- EKDDCG is a not for profit organisation
- EKDDCG is accepted as a charity by the Inland Revenue (ref. SCO18844)
- EKDDCG was formed in 1991. It's objective was to meet with the needs of people with Dementia and their Carers, as Carers themselves felt that the Local Authority facilities in East Kilbride that existed at that time were not able to do this. EKDDCG identified that there would be an ongoing and increased need for their services.
- Current staffing levels are: 6 permanent staff, 3 volunteers, 2 H.N.C. students
- EKDDCG is run by a voluntary management committee.
- 2 SLC Councilors; Cllr Archie Buchanan and Cllr Graham Scott, attend our monthly Committee meetings in a liaison and advisory capacity.
- A representative from South Lanarkshire Council's Older Peoples team also attends our monthly Committee meetings in a liaison and advisory capacity.
- EKDDCG currently supply in excess of 11,000 dementia care hours per year
- EKDDCG currently provides care to 21 service users, with more people on a waiting list for care.
- In addition to dementia care provision, EKDDCG also:

Facilitate a monthly Carers Support Group (so successful that SLC have offered use of Meldrum House to accommodate increasing numbers)

Have a key role within the Lanarkshires Local Learning Network

Has provided Dementia training to SLC staff, local Nursing homes, and Care Providers such as Cornerstone Community Care.

Has sourced training on Restraint and made this available to other local Care providers at cost price.

Has provided support and training to the Gordon Dementia Services in Inverurie.

OUR HISTORY WITH S.L.C.

- Older Peoples Services has been the prime purchaser of care for many years.
- In 2004 Older Peoples Services agreed a contract with EKDDCG to purchase 30 daycare places per week.
- The initial contract agreement has been renewed and is due to expire in June 2009
- SLC advised EKDDCG that the current contract “may go out to tender in July 09”. At no time were we advised that the contract would be taken “in house”. No representatives of EKDDCG, or any of our Service Users and Carers have been consulted.
- The contract price currently in place is as it was in **2004**, as SLC would not enter discussion on price increase. The ‘efficiency savings’ document shows OPS underspent £100, 000 last year
- EKDDCG has continually raised it’s year on year fundraising target to ensure survival of the service
- Fund raising requirement for year 2008 – 2009 is almost £30,000
- EKDDCG has an ongoing belief that they have the experience and infrastructure to increase their service provision. The following examples are indicative of the EKDDCG’s culture to identify best practice solutions, and also to work with S.L.C. on joint venture projects for the benefit of people with dementia and their carers:

October 2006 - EKDDCG submitted expansion proposal to Older Peoples Services Team.

September 2007 - EKDDCG made joint venture proposal to Older Peoples Services Team. This plan included proposal for EKDDCG to re-align dementia care provision & operate Ashley Gant center as dementia unit.

September 2007 - Older Peoples Services Team requested EKDDCG to submit proposals for increase in daycare capacity. They also specifically requested EKDDCG to submit proposal to utilise Parkhall Street facility to provide additional daycare.

In addition, EKDDCG offered the use of their own transport to assist S.L.C. alleviate the severe issues they had in conveying service users to and from daycare at weekends.

On all of the above joint venture discussions (with the exception of the proposal submitted in October 2006) SLC failed to maintain ongoing discussion and the proposals were mothballed. The offer of assistance with weekend transport was not even responded to by SLC.

CARE PROVISION

- EKDDCG operate with a flexible staff to service users ratio of 1:3 max. We aim to provide a safe and secure environment to provide care that meets the changing needs of people with dementia.

EKDDCG also noted the comments below made by Sherrif Alastair J M Duff. We acknowledge that although the remarks were made during a Fatal Accident Enquiry following an incident in a nursing home, they would apply to any care setting.

“The acknowledged propensity of some who suffer from senile dementia to behave in an unpredictable and sometimes aggressive or violent manner”

“The managers of any nursing home should have under constant review the level of staffing required to meet the changing needs of residents, regardless of the staffing levels set by the Care Commission for Scotland”.

- S.L.C. daycare centers in East Kilbride caring for people with dementia operate with a staffing ratio varying between 1:4 and 1:8 dependant on the care facility they attend.
- SLC currently operate a practice of providing care for people with diagnosed dementia in mainstream daycare centres. This would appear to be a cost led service that may not meet the needs of the client.
- By using our own transport, EKDDCG promotes a culture of regular outings and external activities providing our service users with a sense of belonging by being part of their local community and society in general.
- To date this year, EKDDCG has provided 110 outings to Service Users and Carers.
- People with dementia attending an SLC daycare centre are not offered the opportunity of regular outings.
- Our “Ring-round Service” ensures that even when we receive short notice cancellations, we consistently utilise every daycare place we have available. This practice has meant that to date this year, over 100 daycare places have been given to Service Users who otherwise would have received no care that day.
- SLC daycare centers in East Kilbride have no procedures in place to utilise cancelled care places.

The following pages represent some of our ‘Unique’ services, which the Council does not provide, and some comments from our Service Users (with whom we regularly consult and include in decision making).

A summary of trips and outings in 2008

Tea/Coffee, Cakes & Scones!

1. Moncrieff Church Tearoom	30 visits
2. Broadlees Golf Range Chapleton, Tearoom	13
3. Greenhill Country Estate Tearoom	9
4. Clyde Valley Garden Centre.	4
5. Morrisons	1
6. Hunters Pub	1

Lunch

1. Greenhill Country Estate Tearoom	3 visits
2. Largs	1
3. Troon	7
4. Morrisons, East Kilbride	1
5. New Farm Carvery	1
6. Dumbarton Carvery	3
7. Picnics	4
8. Town Centre	1

Places of Interest

1. Strathclyde Country Park	4 visits
2. Barge Trip- Forth and Clyde Canal	2
3. Maidens Beach	2
4. Burrell Collection	2
5. Peoples Palace	1
6. Luss & Loch Lomond	2
7. Calderglen Country Park	3
8. Callendar and Doune Antiques Centre	1
9. Stirling Castle	1
10. Falkirk Wheel – Barge Trip	1

One to One Outings with Service Users

1. Hampden Football Museum	1 visit
2. Ten Pin Bowling	1
3. Snooker	1
4. Football Match	4
5. Swing Band and Jazz Band Concert	1

Evening Outings Including Carers

1. Barge Trip – Forth and Clyde Canal	1 visit
2. Alexander Brothers Concert.	1
3. Party Night with Hired Band/dancing	2

Total 110 outings to date. (as at 14th November 2008)

Service User Feedback

This is a selection of feedback taken from our “Getting To Know You” form.

This section is entitled “*Places I Like to go or Would Like to Go*”, *as identified by our Service Users:*

All outings, Museums, Art Gallery, Burrell Collection, Peoples Palace.

Troon and the coast.

Runs to the Coast, Football Museum, Pub Lunches.

Happy with all outings at the club.

Love all trips and outings.

Happy with all the places we visit.

Peoples Palace, Transport Museum, Football Museum, Barge Trip, Fish Teas

Barge Trips, Trips to Moncrieff Church for tea and cake.

Edinburgh Zoo

The Seaside.

Like to go out for Lunch.

Loch Lomond and Luss. Troon, Prestwick, Ayr and Largs.

Troon, Luss, Museums, Peoples Palace, Strathclyde Park.

Service User Forums - Feedback

These meetings are held with our Service Users on a monthly basis, these are some of the comments made at such meetings (all names changed to protect privacy of our Service Users):

1. **Mrs A particularly enjoys all the trips and outings because this does not happen at the other daycare centre she attends.** (1/03/08)
2. **Mrs B stated that she would be lost without Pine.** (04/07/07)
3. **5 Service Users all like the fact that you are given a choice on outings they can go on.** (01/03/07)
4. **All service users are happy that they are involved in decision-making.** (01/03/08)
5. **Mrs C likes that when at the club she is never left on her own, if she doesn't want to join an activity the staff sit with her and chat.** (01/03/07)
6. **Everyone agreed that the trips out of the unit were excellent with plenty of choice.** (11/02/08)
7. **Happy with choices and any decisions made. Excellent Service, Happy with trips.** (12/03/08)
8. **When asked if everyone felt they were given enough choice within the club regarding activities and the things we do, answers included, “I Love It” and “The club is great”** (05/02/08)
9. **Service Users were asked what they would look for when the club recruit staff of volunteers, Mrs D stated, “follow the examples of the ones who are there, because they are perfect (ten out of ten)”. Mrs E stated “the staff are right for the job, you can talk to them.”** (11/04/08)
10. **Everyone agreed that they are given enough choices in every aspect of the club. Nobody has any complaints and nobody wants any changes.** (31/07/08)

Service User Quotes

These quotes are taken from our “Getting to Know You” form, which is completed *by* Service Users. This section is entitled “*Anything Else You Want Us To Know*” (all names changed to protect privacy of our Service Users):

“I Wouldn’t change anything at Pine, perfectly happy with everything on offer”

Mrs A 29/10/08

“Thoroughly enjoy coming to the club”

Mr B 01/11/08

“I enjoy the friendly company I share with the other club members”

Mrs C 20/05/08

“Very happy with everything at the club. I like the familiar routine.”

Mr D 01/04/08

“I’m not from this area originally, so everywhere we visit is a new and great experience for me”. Mrs E 10/07/08

“I would really miss the club if I couldn’t attend every week”.

Mrs F 29/10/08

“Love all trips and outings on offer at the club”.

Mr G 27/03/08

“I enjoy the company of others in a relaxing, familiar atmosphere”.

Mrs H 29/10/08

“I love all trips and outings”.

Mrs I 29/10/08

Summary

We have taken a retired school teacher to the Scotland Street School Museum; a retired policeman to the Police museum; a retired footballer to hospitality in 2 of his former clubs; numerous Service Users to visit the place of their childhood; and people in their 80’s on an astra-glide and in the dodgems!

This is truly ‘person-centred care’.

Our Service Users may well be offered *alternative* care, but will they be given the same level of choice, inclusion, independence and personalised care? We believe not, and that is why we must fight on their behalf! Listen to what people want!

South Lanarkshire Council may try to avoid consultation with the people who’s lives will be affected by this proposal, but that is not an option for anyone who truly believes in Person Centred Care.

No matter what political party you belong to, I urge you to consider the needs of people with Dementia, and their right to a level of care that meets with their needs.