

East Devon Forget-Me-Not Reminiscence Service: a review of data collection and the development of a logic model.

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Abbreviations

AVVS	Axe Valley Visiting Scheme
DARES	Dementia Education Programme Incorporating Reminiscence for Staff
EDVSA	East Devon Voluntary Services Agency
EQ5d	Euro Quality of Life (Wellbeing measure)
FMN	Forget Me Not
NRES	National Research Ethics Service
ONS	Office for National Statistics
POPPI	Projecting Older People Population Information System
QALY	Quality Adjusted Life Years
RNNI	Reminiscence Network Northern Ireland
RT	Reminiscence therapy
SROI	Social Return on Investment
VCS	Voluntary and Community Sector

Executive summary

This is not an evaluation report of a service or intervention. It does not seek to make any assessment of the effectiveness or cost effectiveness of the Forget-Me-Not reminiscence service. Instead it is a briefing report that highlights the information and data currently collected and collated to help develop a logic model and provide advice on data monitoring to encourage the project to think broadly about what may be required to assess and track its progress in the future.

It is known that the provision of high quality approaches to providing meaningful and enjoyable activities are a key part of enabling people residing in care homes to 'live well' with dementia (Department of Health, 2009).

However a recent evaluation of 17 care homes across three regions of the country, revealed that residents spent less than 13 per cent of the waking day engaged in any meaningful activity (Ballard et al, 2011). Consequently forget-Me-Not is potentially a valuable service.

Looking at the five constituencies that make up Devon, the East Devon constituency has an older age profile compared to the other districts i.e. 29.7% of the total East Devon population are aged 65 years and over (Devon County Council, 2014).

Applying 2007 prevalence rates to ONS population projections of the 65 and over population, an estimated 4,091 people are predicted to have dementia in East Devon by 2025, which represents 22.2% of the total population aged 65 and over in Devon predicted to have dementia by then (POPPI 2014).

This briefing document looks the theory underpinning Reminiscence Therapy (RT) and includes them in the logic model to understand the service delivered by the Forget-Me-Not intervention hosted by the East Devon Voluntary Services Agency (EDVSA).

Our fieldwork interviewing of stakeholders, volunteers, care co-ordinators and staff enabled us to assess and validate anticipated outcomes from the service as specified in EDVSA's business plan (2015).

This report makes suggestions on drastically modifying the current Forget-Me-Not feedback form to make it a more effective tool to assess what was actually delivered in the sessions. Importantly: the number of attendees, the number of staff supporting and the number of volunteers in attendance need to be captured for each session. If added and inputted into the data base this will help with later unit cost analysis and will become a useful measure of quality.

In the absence of any data from existing forms it is recommended that the outcome measures included on the feedback form to be included in a one off survey of care co-ordinators and care homes to discern whether there is any further demonstrable impact on beneficiaries. These questions should not be asked at the end of each session.

Other information captured by the feedback questionnaire should be captured in a one-off enquiry at the start of the relationship with a care home/venue. The information should then inputted on to the existing care home database for later analysis. Additional demographics should also be captured at the start of the relationship with a new e.g. number of patients with dementia.

We make two suggestions for moving forward and capturing evaluation data the acceptance and pursuance of which will depend on funds available and EDVSA's ambition.

Firstly we suggest that a feasibility trial could be conducted in one home that has most exposure to the service. The prime outcome measure could be the Euro Quality of Life wellbeing measure (EQ5d) to

be completed by staff before and after the trial. Quality-adjusted life year (QALY) calculations can be derived with impact validated through interviews with families, the care staff and journals kept by volunteers. This is a standard research methodology used when presenting evidence to the National Institute for Health and Care Excellence (NICE) and an approach supported by the Dunhill Medical Trust.

Our logic model will reflect that more value accrues from the Forget-Me-Not service than simply that stemming from the impact it has beneficiaries. Unlike traditional trials that take a health service or service provider perspective our second suggestion of doing a social return on investment analysis (SROI) will assess and assume that values can occur for a range of different stakeholders.

This report will outline the benefits and challenges of doing both of these approaches.

About this report

This is not an evaluation report of a service or intervention. It does not seek to make any assessment of the effectiveness or cost effectiveness of the Forget-Me-Not reminiscence service. Instead it is a briefing report that highlights the information and data collated to help develop a logic model and provide advice on data monitoring to encourage the project to think broadly about what may be required to assess and track its progress. It is written to address the objectives established by East Devon Voluntary Services Agency (EDVSA) who felt the project needed support to improve data monitoring in order to encourage project to growth. We were asked to develop a logic model. In doing so we explore the assumptions and principles held by the service around how the intervention works. We look at the proposed outcomes established for the beneficiaries of the service and explore these with stakeholders attached to the project. It seeks to propose an evaluation framework for the service describing potential tools, data and processes available to track impact. It starts with a brief literature review which helps us to contextualise the service in terms of demographic profile and intervention availability.

Literature Review

Prevalence of dementia

Based on 2013 population data, there were an estimated 815,827 people with dementia in the UK, of whom 773,502 were aged 65 years and over – this is equivalent to 1 in every 79 (1.3%) of the entire UK population, and 1 in every 14 (7.1%) of the population aged 65 years and over (Prince M et al, 2014). In Devon, the number of people estimated to be living with dementia is around 14,080 in 2015 – this represents 1.84% of the population (Devon Health & Wellbeing Board, 2015).

Table 1 shows the dementia prevalence in 2014 by parliamentary constituency in Devon (Parkin & Baker 2015). These prevalence rates are rates of diagnosis. Given that slightly over half of those with dementia have been formally diagnosed, variations between areas may reflect differences in rates of diagnosis rather than differences in the prevalence of the disease (Parkin & Baker 2015). It is not surprising that East Devon has the highest crude prevalence of dementia, considering that it also has an older age profile compared to the other districts i.e. 29.7% of the total East Devon population are aged 65 years and over (Devon County Council, 2014).

Table 1. Dementia prevalence 2014, by parliamentary constituency

AS rank	Constituency	Dementia register	Crude prevalence	AS prevalence
428	Central Devon	570	0.74%	0.54%
464	East Devon	873	0.97%	0.51%
401	North Devon	804	0.77%	0.56%
287	South West Devon	712	0.79%	0.60%
282	Torridge & West Devon	890	0.88%	0.61%

AS = age-standardised

A review of academic evidence undertaken by the Alzheimer's Society (2013) suggested that over 80% of people in the UK, who live in residential and nursing homes, have dementia and/or significant cognitive impairment.

Cost of dementia

The total cost of dementia to society in the UK is £26.3 billion, with 44% of this amount contributed by the work of unpaid informal carers, usually spouses or adult children of people with dementia (£11.6 billion); the other costs are related to healthcare (£4.3 billion) and social care (£10.3 billion; 17.2% of the total cost of dementia is publicly funded, 22.9% of the total is privately funded) (Prince M et al, 2014).

The total number of unpaid hours of care provided to people with dementia in the UK is worth £1.34 billion (Prince M et al, 2014). Informal care accounts for 74.9% of the total cost for all people with dementia living in the community (Prince M et al, 2014). There are around 706,000 informal carers in the UK currently (Lewis F et al, 2014). A Carers Survey in Devon found that 32.5% of respondents were caring for someone with dementia compared to a national survey figure of 25%, and 31% of all carers were older people compared with 25% nationally (Joint Commissioning 2014-2016).

Projections of prevalence and cost of dementia

The UK is benefiting from an extension in our life expectancy. Based on 2012 population data, it is predicted that by 2025, the total population in South West England aged 65 and over will reach 1.4 million, with 16% of this total figure residing in Devon (ONS 2014, reported by Projecting Older People Population Information System (POPPI)). Projections show that 33.5% of the total population in East Devon will be over the age of 65 by 2025 (ONS 2014, reported by POPPI).

Figures taken from the General Household Survey 2007 show that the total population aged 65 and over living alone in Devon in 2025 is expected to be 87,060, with 21.5% of this amount being resident in East Devon (Office for National statistics 2011, reported by POPPI). By contrast, the total Devon population aged 65 and over living in a care home with or without nursing in 2025 is expected to be 8,732, with 21.9% residing in East Devon (ONS 2011, reported by POPPI).

As the population ages, there will be a greater proportion of people living with dementia and more of the country's resources will be required to care for them. It is estimated that by 2025, there will be approximately 1.1 million people with dementia in the UK (Lewis F et al, 2014). Applying 2007 prevalence rates to ONS population projections of the 65 and over population, an estimated 4,091 people are predicted to have dementia by 2025 in East Devon, which represents 22.2% of the total population aged 65 and over in Devon predicted to have dementia by 2025 (POPPI 2014).

Consequently, the total cost of dementia in UK is estimated to rise to £32.5 billion by 2025 (expressed in 2011 price terms), with the majority of that being the costs of informal care – mean estimate of £17.5 billion (Lewis F et al, 2014). If there is no significant change to treatment options, this would correspond to a 36.4% increase in the demand for informal carers by 2025 (NICE, 2006). Factors like declining fertility rates, shifting burden of care, and changes to social structure, raise concerns that a supply of informal care on that scale might not be available (Lewis F et al, 2014).

Strategies and challenges to tackle dementia

The Joint Commissioning report: Living well with dementia in Devon 2014-2016 lists some of the progress that has been made so far to improve services and outcomes for people with dementia and their carers. Establishing an integrated dementia care pathway supported by the Dementia Road Map, and setting up several dementia-friendly communities are among the achievements made county wide (Joint Commissioning 2014-2016). Achievements made in Devon are as follows (Joint Commissioning 2014-2016):

- Devon Dementia Care and Support Partnership with independent, statutory, voluntary and community sector partners
- 38 peer support memory cafés
- Devon Carers Centre reaching more carers
- Extra care housing developments inclusive of people with dementia
- Independent sector care home Kite Mark peer review pilot
- Care Homes Futures programme to develop Dementia Centres of Excellence
- Intergenerational projects with seven schools as part of a national pilot
- Library Memory Groups for people with memory loss and their carers
- A Devon Card to help families use Direct Payments

The East Devon Volunteer Support Agency (EDVSA) has been hosting the Axe Valley Visiting Scheme in the Axminster and Seaton District areas since May 2013. The project provides a visiting service to people aged 60 and over living in their own homes or in residential care homes, and in receipt of health and social care services. Their aim is to alleviate social isolation and improve the health and well-being of those who may be feeling out of touch, lonely, and isolated for a variety of reasons. As of February 2016, forty-six isolated older people in and around Axminster have received individual one-to-one visits

from a volunteer visitor since project initiation - thirteen of these are ongoing, with several more pending (Larsson A, 2016; Carson C, 2016).

Another project run by the Axe Valley Visiting Scheme for older people living in the community and in residential care in Axminster, Seaton and Honiton, is the Forget-Me-Not Reminiscence Service. This project uses a Reminiscence Box containing objects related to the past to trigger memories, and is thought to be particularly useful for people with dementia. The next section will discuss the use of reminiscence therapy in dementia care.

In spite of current progress, commissioners acknowledge that the following key areas still need to be addressed (Joint Commissioning 2014-2016):

- Opportunities to build more integrated, person-centred interventions that recognise people's physical, mental and emotional health needs in both urban and dispersed rural communities
- Continued work with the social care provider market and voluntary sector to develop dementia-specific capacity, quality and variety in the services available, especially as more people exercise choice through personal budgets and direct payments
- Establishing effective, community-based options to ensure that any consideration to transit to a care home is the result of a positive decision
- Improving the knowledge, skills and 'ownership' of dementia across the health and social care workforce
- Reporting transparently on progress in delivering better care, treatment and support linked to the Dementia Declaration outcomes, and giving people with dementia a voice in determining how services are arranged and delivered

The extent of implementation of the National Dementia Strategy locally remains quite varied, owing not only to the complexity of commissioning effective dementia services, but also to cuts in local authority budgets and a constraint on NHS resources. However, the implementation of health and social care reforms have offered opportunities for commissioners and providers to collaborate and integrate these two areas in a whole systems approach to tackling dementia (Alzheimer's Society & MHP Health Mandate, 2011). The Strategy advocates person-centred approach, which essentially requires the integration of evidence-based psychosocial approaches to complement existing medical and neurological models of service delivery, in order to achieve a good level of personalised care for people with dementia (Dempsey et al, 2014).

Reminiscence Therapy (RT)

Reminiscence therapy (RT) is a psychosocial intervention commonly used in older people with mild to moderate dementia. Healthcare literature provides various definitions and conceptualisations of reminiscence, although they often contain similar components. Following a concept analysis, Dempsey et al (2014) proposed to define reminiscence in individuals with dementia as *'the deliberate use of prompts, for example photographs, smells, music and questioning, to promote the recall of pleasant memories. The focus of reminiscence work is to stimulate the person, provide enjoyment and foster a sense of achievement and self-worth. The anticipated outcomes of reminiscence work are enhancement of the person's quality of life, behaviour and mood'*.

RT is popular for several reasons: it works with early memories, thereby focusing on the preserved abilities of people with dementia, rather than their levels of impairment (Dempsey et al, 2014); it is a flexible intervention – it can be planned or spontaneous, a one-to-one or group activity and, as defined above, can be delivered using different media (Cooney et al, 2014). However, despite its popularity, literature on dementia often laments the lack of evidence from high-quality or sufficiently robust studies to support the use of RT as an effective healthcare intervention (Cabrera et al, 2015; Cooney et al, 2014; Dempsey et al, 2014). Moreover, given the associated complexities and challenges, available evidence is limited to people with dementia in care homes, with none related to those living outside these settings.

A large randomised trial of a reminiscence-based intervention – the Dementia Education Programme Incorporating Reminiscence for Staff (DARES) – found tentative evidence that RT has the potential to impact positively on depression, and thus the quality of life of residents with dementia in long-stay care (O'Shea et al, 2014); similar conclusions were suggested by Gonzalez et al (2015) and Testad et al (2014). There was more confident evidence on other benefits of RT to this population: RT encourages intrapersonal self-evaluation and creates an inclusive and supportive social environment that fosters positive interpersonal relationships, and reinforces one's own sense of competence, integrity, and wellbeing (Gonzalez et al, 2015; Cooney et al, 2014; Dempsey et al, 2014). RT also improves mood, creates a sense of continuity, and helps retain a sense of self-worth and identity (Gonzalez et al, 2015; Testad et al, 2014). Another important benefit of RT is increasing one's autonomy and environmental mastery i.e. the perception of control and the ability to adapt to changes that may occur, thus prolonging the time it takes to become dependent in performing daily tasks (Gonzalez et al, 2015).

A grounded theory study carried out as part of the DARES trial, generated the theory of 'seeing me (through my memories)', which explains that through reminiscing and engaging with the resident with dementia, care home staff begin to see the person through the mirror of their memories (Figure 1; Cooney et al, 2014). The study provides insight into the experience of RT, not only from the perspective of the resident with dementia, but also from the perspective of staff. Benefits of RT were shown to be far-reaching: it provides family with the assurance that their relative was better known and cared about as an individual (as opposed to cared for), thus alleviating the burden of 'preservative care' i.e. the need to assume responsibility for preserving the person's dignity, connections and sense of control (Bowers, 1988 in Cooney et al, 2014). It also positively impacts the quality of life of the wider group of residents living in the facility, and brought job satisfaction to the staff (Cooney et al, 2014).

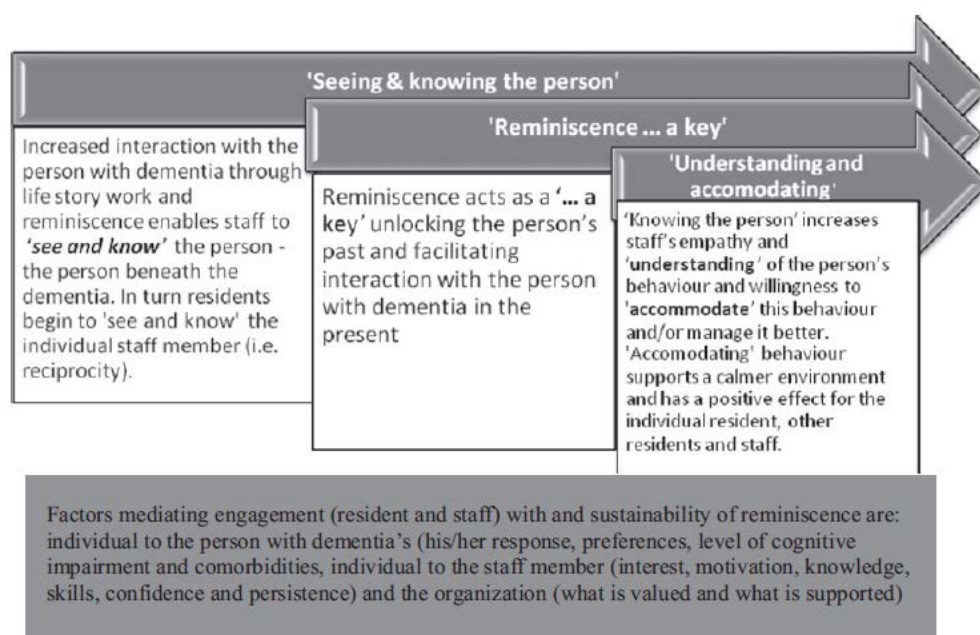


Figure 1.
The theory of
'seeing me
(through my
memories)

(Cooney et al, 2014).

As with many interventions, the success of RT is affected by how well the people delivering and receiving it are engaged with the process. The ability of the person with dementia to engage in RT is dependent on their stage of dementia, co-morbidities, and personal preferences, while staff engagement is impacted by what they value and view as important. The DARES trial found that time was the major limiting factor impacting staff engagement (Cooney et al, 2014). Considering the potential that RT has in allowing care home residents with dementia to lead full connected lives within the constraints of their illness, it is critical for the organisation to embed RT into care plans to sustain it as a long-term investment in

personalised care (Cooney et al, 2014). The President of the Reminiscence Network Northern Ireland (RNNI) encourages RT by stating, *“Growing is a lifetime experience. People, whatever their age, can continue to grow and develop provided they experience the right nurturing conditions.....To understand why someone is as they are now ... it is necessary to know something about what has gone before and what meanings the person attaches to their life experience in the present. This means learning to listen to people’s stories, to what is said, and also unsaid – to become finely tuned so as to be able to read the spaces or silences between the words.”* (Gibson F, 2011, p.19).

Given that the estimated proportion of Devon population aged 65 and over living alone in 2025 will be 10 times more than the proportion in a care home (ONS 2011, reported by POPPI), more research is needed to elucidate the feasibility and potential benefits of delivering RT to people with dementia living in the community. This would complement current evidence, and be in line with the National Dementia Strategy’s objective to improve community personal support services. It is hoped that, ultimately, this evidence would raise the quality of care for and life satisfaction of people with dementia, regardless of the setting they live in.

Background to the Forget-Me-Not reminiscence project

We were told that we would not get anything from her but when we came along we gave her a cricket ball. Yes a cricket ball. Her whole face lit up. It turns out that she used to play with her brothers when she was younger.

From the review of several studies outlined above it is clear that reminiscence services can provide a range of benefits to people with dementia – it can enhance communication, increase a sense of personal identity, improve mood and well-being, and increase the individualisation of care.

There are a number of different approaches and delivery methods for reminiscence work. Reminiscence groups typically involve group meetings in which participants are encouraged to talk about past events at least once a week. Life review typically involves individual sessions, in which the person is guided chronologically through life experiences, encouraged to evaluate them, and may produce a life story book which can be used as a basis for care-planning. Life story work, by pinpointing the likes, dislikes, spiritual and contextual aspects of a person's life, can greatly enhance the ability for care staff to understand and respond to the individual with dementia, and to create a framework for delivering tailored personal care.

Reminiscence work can also help to improve and build relationships involving family, care-givers or volunteers. It is the Alzheimer's Society's view that ensuring that care staff have information about the person with dementia, including their likes and dislikes, has been seen as critical to providing effective support. Within this context reminiscence therapy, and more specifically life story work, has been recognised as offering ways for those with dementia to articulate their needs, and for allowing care and nursing staff to deliver person-centred care. There were until quite recently no Reminiscence/Life Story services in East Devon offering intense one to one support around developing life stories. However the need for a service was highlighted by an independent evaluation of EDVSA's existing Axe Valley Visiting Scheme (AVVS).

Using volunteer support the AVVS scheme provided a useful visiting service to socially isolated people over the age of 60, residing in their own homes or care homes and in receipt of health and social care services in the Seaton and Axminster districts of East Devon. It was identified that those groups of older people who were experiencing declining mental health, such as depression or grief, levels of isolation and issues of dementia which makes

communication more difficult could possibly benefit from a service. A simple befriending scheme, although helpful would not address beneficiaries needs in the same way.

AVVS responded to care home staff requests for more support around reminiscence work. There have been reports that some homes struggle to meet the needs of individual clients. They do not have the capacity, skills or resources to work with the older people and/or their carers to recognise their individual resident's personal histories, personalities and preferences. Equally, they do not have the capacity or skills to engage with these clients in a social and/or caring role.

Subsequently, the Forget-Me-Not reminiscence service developed to address this need with an aim and an intention to improve the care and well-being of older people based in East Devon, by seeking to reduce social isolation - particularly for people with memory loss and signs of depression, through the provision of their reminiscence services.

The Forget-Me-Not reminiscence service is principally aimed at older people aged 60+ who have been identified as having dementia, communication difficulties or who are showing signs of depression. Beneficiaries of the service could be older people living at home or resident in a care home. Its explicit objectives:

Objective 1. To improve the wellbeing of older people by providing them with opportunities to re-affirm their identity and achievements, resolve issues, and feel validated.

Objective 2. To maintain the connections of older people in the community and increase sociability.

Objective 3. To maintain relationships with families and build resilience as the disease progresses.

Objective 4. Within Care Home Settings to promote connections between staff and the people they support, leading to a better understanding of how to provide person centred care, helping to create much richer assessments and care plans.

Objective 5. To improve care standards through training and support for staff in care homes.

The anticipated outcomes from the project include and specified in the business plan were:

- Improvement in wellbeing
- Building of relationships

- Change the staff approach to care in homes
- Improves the end of life experience for families

The Forget-Me-Not reminiscence service was designed to fit around other events that the care home may manage. The Forget-Me-Not reminiscence service co-ordinator works hard to develop strong relationships with the activity co-ordinators in homes so that the service can be conveniently located alongside their normal routines and other activities that the home deliver. The service is usually delivered by two volunteers: a facilitator and a helper. They will attend at the home at an agreed time bringing with them a reminiscence box based around a theme:

- Christmas Past
- School days
- In the kitchen
- Looking good
- Life on the home front
- Royals
- Stars of stage and screen
- Tools and gadgets
- Staying Healthy
- Holidays
- Staying well
- Wash Days
- Where in the world?

The reminiscence boxes have been developed collectively by the staff and will contain a variety of stimulus material: pictures, objects, sounds etc. which the volunteers present to the beneficiaries, engaging them in conversation about the objects presented. The boxes contain items that are seen as likely to stimulate all of the beneficiaries' senses including touch and smell. This often stimulates small group conversation which releases the volunteers to move onto other beneficiaries in the room to get them involved in reminiscence work.

The Forget-Me-Not experience can potentially fit into the memory café experience which tends to support people living with dementia in their own homes and their carers. Memory cafes are connected to a range of other communal activities. The Forget-Me-Not reminiscence service have visited the nostalgic cinema in Honiton which offers dementia friendly screenings and other communal events. It has done work with Honiton Dementia Action which is an awareness group that gets local stores and pharmacies involved in being aware about dementia users of their services.

But engaging with beneficiaries in a care home can be challenging. The number of residents participating can vary. We heard one report of just 5 people participating at one reminiscence event. This was because there was a day's outing planned on that the day arranged subsequent to the initial Forget-Me-Not reminiscence service booking. There have been occasions where two volunteers may have had to engage up to 30 people in a session. At these sessions the volunteers will ordinarily attempt to get the beneficiaries to sit in a circle but this isn't always possible due to numbers and room layout. Visiting family members and carers can usually adapt to the event and similarly engage with the activity delivered by the service.

Funding from the project initially came from Axminster Community Hospital League of Friends. In January 2016 additional funding was received from Dunhill Medical Trust. They contribute £21,551 of the £37,188 budget for 2016. The rest of the income is made up by contributions from Axminster Community Hospital League of Friends, EDVSA and fees for services. The programme is funded by Dunhill Medical Trust for three years up until 2017. The grant of £88,960 covers the cost of a part time co-ordinator (£37,849) with expenses of (£2,950). Volunteer expenses for training (Direct-training includes: dementia training, a life stories course and dementia awareness), transport, subsistence and DBS checks cost £16,098. Management costs account for £7,077. With the remaining £24,986 going on running costs for the boxes, telephone, rent, activities and community events.

To date (June 2016) there had been 153 Forget-Me-Not reminiscence sessions delivered over 15 months to 29 different venues in East Devon. 8 venues have had just one visit; while 1 venue has had 55 visits. Some venues simply give a donation for the service, but the majority pay £25 + VAT. This is collected by the Forget-Me-Not co-ordinator.

Additional value for the project comes from the individual volunteers. Not only do they deliver the Forget-Me-Service in care homes and the community but they also organically help the project to grow in various ways. Principally by adding to the boxes in creative and imaginative ways to supplement the experience in the homes they visit. This has included bringing in flowers from the garden, material from the internet (including old photographs and sheet music) and small percussion instruments. With a regular commitment to a home volunteers evolve their sessions to meet the needs of different people and they are prepared to work intensely with recognisable individuals who were less engaged on previous visits.

This report is written to address a few objectives that the EDVSA felt it needed in order to encourage the project to grow. We were asked to develop a logic model – testing out the

assumptions and principles within the service around how the interventions lead to the proposed outcomes with services users that have been identified by key stakeholders. It seeks to propose an evaluation framework for the service describing the tools, data and processes available for track impact for beneficiaries.

To enable us to get a greater understanding of the project we approached and interviewed key stakeholders identified by EDVSA and the project co-ordinator. This included:

- 1 x Housing court manager
- 11 x Activity co-ordinator in care homes
- 1 x Receptionist/administrator of a care home
- 1 x Memory café co-ordinator
- 4 x Volunteers
- 7 x Parents visiting their family member in the home
- 4 x Additional Stakeholders

We also saw and participated in Forget-Me-Not sessions in three different care homes and interacted with beneficiaries.

What is the impact of the Forget-Me-Not reminiscence service?

The anticipated outcomes from the project identified by the service (EDVSA, 2015):

- Improvement in wellbeing
- Building of relationships
- Change the staff approach to care in homes
- Improves the end of life experience for families

Our field work explored these impacts with our interviewees to see if they are impacts that could be validated and therefore included in the logic model.

Improvement in wellbeing

It is very clear from our interviews and observations that those people who witness the sessions (staff, activity co-ordinators, family members etc.) feel that the beneficiaries generally who attend the Forget-Me-Not reminiscence services really enjoy the service. They welcome its engagement with their residents and relatives and generally describe the service using positive descriptors:

It's fun and they enjoy it

(A carer)

It is always quite well received by our staff. All really good fun I suppose.

(Care Home activity co-ordinator)

It is actually a very nice idea and very helpful to a home

(Beneficiary's daughter)

They bring a fresh energy to the home

(Care Home activity co-ordinator)

It is not a session, it's just another fun event that we look forward to on our calendar.

(Care Home activity co-ordinator)

The volunteers are the most vocal advocates for impact because they deliver the service and provide the stimulus material for the beneficiaries.

We hear amazing stories all the time. I remember we were doing Life on the Home Front. We heard all sorts things of what happened in these parts during the war. There were stories about feeding returning troops from the war being fed chips. And the occasional bomb drop. It made the past very vivid for them and for us.

(A volunteer)

There are also many interesting people that are invited to the sessions. This includes former local politicians in one home and an international ballet dancer in another.

But it is important to understand what the intervention Forget-Me-Not reminiscence service is. By and largely it is quite a brief intervention for most beneficiaries. Their experience may last around a hour and a home may have a visit from them a few times a year. In fact most of the homes have had fewer than six visits. So for many beneficiaries there will not be an on-going experience of the Forget-Me-Not intervention. The service is not used to sustain reminiscence beyond the immediate exposure of the service at the session. Each session is a new session. It does not necessarily build on previous exposure. And in reality the volunteers can only talk to and engage a few beneficiaries at a time. Which is broadly welcomed and works well but it cannot reach everyone for the whole hour. In some homes the local staff will join in and support the volunteers while in others there is less engagement. In fact in one home it was seen as an opportunity for the care staff to vacate communal areas to do something else e.g. catch up with paper work.

And what Forget-Me-Not needs to do is to make sure that the staff are there to assist and help. They shouldn't disappear for other things. They should be there to support. Leaving them alone is a very unfair deal. The volunteers are not paid as much as the staff and yet they are there alone working with the residents. It is very, very unfair. That's is the fault of the home staff.

(Former care home activity co-ordinator)

What is good about the model is that the Forget-Me-Not team can adjust and go with the flow of what happens on the day of their session. They are able to adapt to things around them and the needs of the people they work with. It takes confidence and skill to do that. It's definitely something they feel collectively part of rather than simply delivering a service developed elsewhere.

So it is clear that the Forget-Me-Not reminiscence service does bring a lot of enjoyment to their beneficiaries. And if it sits alongside other stimulating activities it can certainly help to generate improved well-being amongst its beneficiaries.

Building of relationships

One of the interesting observations we obtained from the interviews were that many of the activity co-ordinators in the care homes saw the Forget-Me-Not co-ordinator as the vital person to developing the link between themselves and the service. She was key to getting the Forget-Me-Not service into the home. They were pleased to hear the passion that the co-ordinator showed for the service and the considerable time she took to develop their relationship and reassure them about the Forget-Me-Not offer. In some cases I heard that managers and owners of homes were sometimes quite indifferent to activities and could perceive them as a hassle to the normal service delivery; but engagement with the project was contingent on the development of a good relationship and understanding between the Forget-Me-Not co-ordinator and the local activity co-ordinator. So the strength of a good project relationship exists largely at this level than anywhere else. And there is a lot of leg work to do in order to get new things going.

Even if there is a care manager that is open to new ideas we struggle to get things going. I have to introduce the idea to the staff which can be a struggle. They may not see it as their role to engage with new activities

(Care Co-ordinator).

It is therefore a credit to the service that this strong relationship has been fostered in a time where austerity and shrinking budgets means attempting new innovative interventions are more challenging. So this has been achieved in a situation where there is a shortage of money. The service is sometimes delivered in homes where some care home staff may not want to engage and where management of the home may not want to reciprocate or sustain the relationship. A frequent refrain from all the activity co-ordinators is that they perceive they have insufficient funding for delivering new and innovative activities.

There isn't the time to deliver this effectively. You are running all the time to keep up and just manage the normal things required with care. You are running to make sure that you are with the CQC. We don't work as a team in our homes we just work to deliver

(Activity Co-ordinator).

The suggestion that the Forget-Me-Not service builds relationships was primarily aimed at developing links to local care homes. But there have been other strong relationships that have evolved from the development of the service. Primarily it is the relationship between

the Forget-Me-Not service and the volunteers. It is also the relationships they have been built between themselves and the community they serve.

This in many ways is a key area of impact that needs to be explored by EDVSA and maybe the Dunhill Medical Trust in the future. It is clear that the project is broadly welcomed by at least some staff in the care homes who perceive that their residents benefit. But additional impacts are being made in volunteer lives in a myriad of ways. Most volunteers spend a considerable time engaged with reminiscence work. Some work with specific homes on a regular basis other are more peripatetic and visit a series of homes.

Before taking up volunteering I was at a bit of a loss as to what to do. But now I have a greater sense of purpose in life. It has given me something meaningful to do which I had lost when I retired.

I had spare time and needed something to do. This gives people something purposeful to achieve. Particularly for those retiring and/or who have moved to here to retire. It gives a focus and allows for sharing of experiences.

I enjoy making it better for others.

I saw the care that my father had and it wasn't that good. There was no stimulation in his home so seeing this is inspiring.

(Reflections by Forget-Me-Not volunteers)

In addition to the skills that volunteers develop through their training individual volunteers can bring a life time of personal experience but also training from their previous careers to the Forget-Me-Not service. One volunteer who had a very stressful and *full-on* professional life talked about the training in *empathy* she received from a large public sector employer that enabled her to engage with beneficiaries who may not be as an engaging as others in care homes with their Forget-Me-Not service.

But there are developing relationships happening beyond the anticipated official circles of the project. Our interviews reveal that contact with beneficiaries is sometimes a starting point for other things. It can help to end volunteer social isolation. There is considerable praise for the project's ability to match volunteers. But companionship has grown between and within the volunteer group and back again into the volunteer home.

Getting out of the house and away from partners is great. But it is the joy of engaging with people that helps. It gives me purpose in life and it was wonderful

for both of us. I get real joy seeing that we are making a difference in older people's lives.

(Volunteer)

So there is evidence that good relationships have been nurtured by the Forget-Me-Not reminiscence service. But it is the links between the co-ordinators and the service and the relationships between the volunteers where additional benefits have been made.

Change the staff approach to care in homes

It is clear that the care homes generally welcome the service. Only one co-ordinator was critical of the service. It is clear that the service is delivered differently in different homes and can be supported variably on the day depending on what else is going on in the home. There is some evidence that the staff try to build on the memory stimulation that has been experienced by the residents:

It often has a snowball effect so that some of them go on to talk about it later in the day encouraging others to join in. We will then mention it at tea or meal times on that day.

(Activity co-ordinator)

And some activity co-ordinators tended to believe it was more effective in stimulating memories compared to other activities like singing. And it certainly is perceived as a lot cheaper than singing sessions.

Forget-Me-Not probably encourages conversation more than any other activity that we do. When the singers come people either sing or they don't but with Forget-Me-Not they are all talking.

(Activity Co-ordinator)

However no activity co-ordinator saw the Forget-Me-Not service as changing what they delivered in the home. Instead the Forget-Me-Not service was seen more as helping them to provide an interesting activity in an already established portfolio of activities.

Improves the end of life experience for families

It was extraordinary hard to see any evidence to support this impact. The carers we spoke to in the care homes who were visiting their relatives (although pleased that the activity was

taking place) had not heard of the Forget-Me-Not service and did not anticipate that it was anything different to any other activity they may have experienced on another visit. The activity co-ordinators also failed to see this as a potential impact of the service. If it was delivered more intensively over time or as a one-to-one activity in a memory café then there may be a greater impact in terms of encouraging reflection on a life led.

Data collection

Currently there is a lack of clarity about what data is and should be collected by the Forget-Me-Not co-ordinator. At the moment there is an Excel based spread sheet that usefully records:

- The care home/memory café/event visited
- The theme of the reminiscence box
- Date of visit
- Cost of visit
- Method and time of payment

Additionally, the project has been trialling a post-session feedback questionnaire. It is quite a long questionnaire and is intended to be completed after the session. It contains the following questions.

1. What did you hope the sessions would achieve?
2. How many of your residents have a Dementia diagnosis?
3. Effects on clients after the session?
4. Effects on mood or behaviour?
5. A question on effects on clients if the service continued?
6. A question inviting implications for paying for the service once the funding reduces
7. Any other comments or suggestions?

Questions 2, 3, 4 and 6 are fixed response questions. Questions 3 and 4 use a valorising scale where those completing the scale are asked to mark 1 as high/agree and 4 as low/disagree. It is quite a long questionnaire for busy activity co-ordinators to complete. There was also a lack of clarity about how to feedback/return the form from organizations hosting the Forget-Me-not sessions. We were twice offered a completed feedback form from a care home that previously received a session. Thus the activity co-ordinators were unclear

whether they should give it to the volunteers or they were going to be asked later to forward it back to the Forget-Me-Not service. A few activity co-ordinators also said that they would prefer to complete it electronically to avoid confusion.

However the feedback form is problematic because it is trying to do a range of things. It is trying to collect demographic information, assess impact, invite a value judgment about funding which would require further enquiries of beneficiaries and budget holders to give a valid answer and then a general enquiry to provide comments or suggestions? A further problem stems from the questionnaire's pre-amble. There is no consideration given to explaining whether this information is given in confidence, how it would be stored and if it would be reported on in any external reports. There is just an assertion that it is:

To help us provide a quality service to your clients and to assist us in applying for further grant

It would be advisable for the project to think through what information it really wants to collect and then the ethical implications of the preamble could be reassessed.

There are also challenges around the instructions on how to complete the form:

Please rate 1 as high/agree and 4 as low/disagree and if possible, give real life examples of any specific outcomes. Thank you

It would be better to simply ask either agree or disagree and then use a Likert scale to measure the intensity of the choice. It is not clear what High or Low means alongside agree or disagree. Various kinds of rating scales have been developed to measure attitudes directly. The most widely used is the Likert Scale. Likert (1932) developed the principle of measuring attitudes by asking people to respond to a series of statements about a topic (in terms of the extent to which they agree with them) and so tapping into the cognitive and affective components of attitudes. Which is what is being attempted here; in this feedback questionnaire. Likert-type or frequency scales use fixed choice response formats and are designed to measure attitudes or opinions (Bowling, 1997; Burns, & Grove, 1997). These ordinal scales measure levels of agreement/disagreement. Most commonly five options are provided:

Strongly agree / agree / don't know / disagree / strongly disagree

Note there is a clear neutral option when using a Likert scale. The current feedback questionnaire does not provide that option. Also these instructions concerning completion need to be nearer the actual questions and not given before an open response question as in this case.

Looking at the questions in general we feel that some of these questions should now be superfluous to needs. Question 1 asks: *What did you hope the sessions would achieve?* This a general question that seems to be inviting comments on the whole Forget-Me-Not experience at the care home/event. It is probably superfluous in the sense that service might already know and have discussed what the sessions should attempt to achieve and that is why they signed up for the service in the first place. These aspirations should be captured during the first contacts with a care home or place or activity and recorded as a one off and noted on the database that records all the information on number of sessions, payments, dates etc. It should not be repeatedly asked. If it is a question about a particular session then it can be kept on the feedback form but monitored to see if it is actually giving any new information.

Question 2 asks: *How many of your residents have a Dementia diagnosis?* The co-ordinator is then offered some (not mutually exclusive) responses. Again this is a question that should be asked at the beginning of the relationship with the care home or place or activity. The information should be recorded on the database and not repeated. It is better to invite percentage guestimates which helps with later evaluative work. What could also be beneficial is a request as to the gender balance and whether there are any special needs or different communities of identity in the care home (eg, ethnicity or ex service personnel particular navy). Again it should be a one off question asked at the start of the relationship.

Questions 3 and 4 explore the impact of the sessions on clients and the effects on their moods after the session? It is not clear what amount of feedback has been received and/or collated in response to these sessions. Has there been sufficient collected for a reasonable judgment to be made about these impacts to ensure that the exercise does not need to be repeated? If there has been then the questions could be dropped. If not then these questions should be asked in a separate survey around impact that is done as a one off exercise. It is highly recommended that Likert scales be used and homes are invited to respond to them if they wish too. An example of appropriate pre-ambles and ethics advice can be provided. But clear thought as to the engagement of the homes in this exercise needs to be made. The questions can then be dropped from the feedback form.

Questions 5 and 6 are concerned with fees. Question 5 is a hypothetical question about withdrawal of service and impact on clients. This should be dropped from the feedback questionnaire. Consideration could be given to its inclusion in a one off survey but it should definitely be avoided on the feedback form. Hypothetical questions make bad survey questions. Question 6 seeks to engage the area co-ordinator in commenting on something they would not necessarily be able to answer. Again we would advise dropping this question. If the service would like to undertake a survey of the home then we could advise on a 'Willingness To Pay' type questions that have been devised by health economists to fit into the survey.

The most appropriate question for a feedback questionnaire is Question 7 which should be retained. All the area co-ordinators were generally happy with the Forget-Me-Not reminiscence service. They would also welcome a simple feedback form to return to EDVSA about their experience of the session. Preference of mode of communication for feedback will vary. Again this is something that can be established at opening discussions with new venues as to the most convenient mode. Some would prefer to do e-mail feedback whereas others would prefer paper so that they can discuss impact at team meetings enabling the home to reflect on the things that worked well. Some of the feedback we picked included:

It would be interesting if we can have things to taste but we would have to look at swallowing issues and allergies.

Equipment that can be put to use and get them more involved in physical activity.

It needs proper time to prepare before the project arrives. It should be done in a dedicated space with staff available to intervene if issues like coughing or a need to leave the area arises.

They could tailor events to suit the local area or national events. The Royal Box went down well at the time of the queen's celebrations. And photographs of the local town from decades ago also seems to go down well.

It would be good to be reminded about what is available through an e-mail so that we can build them into our planning of activities.

The 55 Centre offer lunches and activities, it would go down a storm there or in the community hospitals who are particularly working with patients in recovery.

They need to proof read some of their material I was slightly embarrassed by the typos and misspellings on one paper.

I suggest that two could perhaps best work with about 6-10 residents.

The last point is important. At the moment the feedback questionnaire does not seek to invite demographic information about the session. The activity co-ordinators are not asked to say:

- How many residents attended the session?
- How many volunteers attended the session?
- How many staff supported the event?
- Where was the venue?

This would be vital information to collate on a feedback form and should be recorded on the database and used to quality check the delivery both in terms volunteer/beneficiary ratios and staff support/volunteer ratios. The three sessions we attended seemed to vary on these factors. It is something that the volunteers might like to feedback and discuss at future gatherings to review the service. Plus, having this kind of data would help in subsequent economic analysis. Particularly when it comes to unit cost analysis.

Moving forward

It is known that the provision of high quality approaches to providing meaningful and enjoyable activities are a key part of enabling people residing in care homes to 'live well' with dementia (Department of Health, 2009). This is also an important part of preventing and treating behavioural psychiatric symptoms associated with Alzheimer's disease. Alzheimer's Society research studies using Dementia Care Mapping, i.e. the collection of feedback from service users, reveal that many care home environments are very unstimulating for people with dementia. For example, in an evaluation of 17 care homes across three regions of the country, people spent less than 13 per cent of the waking day engaged in any meaningful activity (Ballard et al, 2011). The work of the Forget-Me-Not reminiscence service helps to give some of East Devon's dementia sufferers a stimulating experience a few times a year.

This report has made recommendations about improving data collection for monitoring purposes and improving the database simply using the existing Excel spreadsheet to ensure that outcomes can be recorded or measured. At the moment it is not clear what outcome data is actually available to do an initial analysis based on the original outcomes selected for the feedback questionnaire. Nevertheless analysis of what is available should be undertaken if not we have recommended undertaking a one-off survey of care venues using existing items but with amendments to try and capture impact. The feedback questionnaire should be shortened to include items that address the volunteer/beneficiary/support staff ratios to ensure the care homes and venues have an optimal balance to more effectively benefit from the service. At the moment there is no clarity about what is happening when the enthusiastic volunteers go to deliver a vibrant service in the community.

Once this is addressed and adequate support and clarity is given to data collection around the service, particularly in terms of getting an appropriate feedback questionnaire and having a database that collates basic information around attendance numbers, volunteer ratios, support staff ratios etc. then the service will be able to start an appropriate monitoring system with a reduced burden on the volunteers and the activity co-ordinators in the care home. The latter are very willing, in fact want to provide feedback, but they need the service to be flexible in how this is collected. As a multi-site intervention this will require a lot of administrative back up. So the service will need to allocate adequate resources to develop and track the service. The Forget-Me-Not co-ordinator will need support to do this because it is very time-consuming.

In terms of trying to effectively measure the impact of the service to ensure that the project is embedded in the community with funding that will sustain it into the future to meet the identified and high demand that continues to grow in East Devon there are two potential evaluation framework routes it could explore in order to assess impact of the service based on the logic model developed here.

The service is enthusiastically liked by most of the stakeholders we spoke too. In most care homes the Forget-Me-Not service has visited 6.17 times. There is an outlier which is the Koppers that has had 55 visits in the period explored. If we take the Koppers out of the database (June 2016) then the service has been in the care homes on average 4 times over the period of the intervention. This isn't a great deal of exposure to the service for the beneficiaries. So logically impact may be quite limited and measuring it a real challenge.

However to measure impact and fully evaluate the Forget-Me-Not reminiscence service there are two options that are potentially feasible. We are assuming that the suggested data monitoring collection practices outlined in the previous section are in place and impact data is now regularly recorded on a database. One way of assessing the service is looking at the home where it has most the most exposure. There is one care home that has the maximum exposure to the service; that is Koppers in Axminster. Koppers is a Specialist Memory Care Home; who are committed to the compassionate caring of older people who are experiencing issues with memory loss and mental health complications. But like other care homes there are other initiatives and projects happening in the home. However a small feasibility trial could be run where a small group of residents receive the Forget-Me-Knot experience over the year. If the service is operating optimally this could be 2 regular volunteers working with 12 residents. The remaining 12 residents do not receive the service. It would then be appropriate to then use a standard wellbeing tool with carers and staff to assess wellbeing. Typically this could be Euro Quality of Live wellbeing measure (EQ5d)

The EQ5d is a standardized instrument for measuring generic health status. It looks at five dimensions of health. It is used for estimating preference weight for that health status, then by combining this measurement with time, a quality-adjusted life year (QALY) can be computed. QALYs gained are used as an outcome in cost-utility analysis which is a type of economic evaluation that compares the benefit and cost of health care programs or interventions. In this case it would be against the usual practice of the home. Validation of impact could come through interviews with families, the care staff and journals kept by volunteers. Medical records could also be used to assess any difference in service usage and prescriptions.

This will probably be a challenging piece of research to undertake. Ethical approval through National Research Ethics Service (NRES) would be needed. Permission of the home, the beneficiaries and their families would need to be sought and the researcher would need to spend a lot of time in the home understanding and operationalizing the intervention. It would also be quite expensive to undertake but it would demonstrate whether scalability is feasible for an intervention using the standard research methodology deployed by National Institute for Health and Care Excellence (NICE). A full trial in more contexts could then be considered if the outcome is seen as cost-effective.

An alternative approach is to consider undertaking a Social Return on Investment (SROI) analysis. Successive governments have encouraged businesses and services to focus on outcome and impact, which along with the concept of 'value for money', is now becoming a growing concern within philanthropic sector (Leat, 2006). Using the SROI methodology is now officially accepted is an appropriate method for assessing value in the third sector (Cabinet Office, 2009). It enables third sector providers and commissioners an opportunity to see the broader value that third sector organizations can bring to their local communities. In essence SROI approaches compare the monetary benefits of a program or intervention with the program costs (Phillips, 1991). In this sense SROI represents a development from traditional cost-benefit analysis as practiced by Grant et al (2000) when they assessed the cost-effectiveness of the Amalthea project. Developed in the late 1990's it aims to fully valorise all social impacts of any intervention (Emerson, 2000). SROI therefore works to demonstrate the extent of this value creation by measuring a range of social, environmental and economic impacts, using monetary values to represent these impacts and enabling a ratio of benefits to costs to be calculated (Cabinet Office, 2009).

It is fairly clear there is more value in the Forget-Me-Not service than simply the impact it has on beneficiaries. Unlike traditional trials that take a health service or service provider perspective, SROI assumes that value can occur for different stakeholders. It is clear from developing a logic model that the volunteers and some care staff get a lot from the service, possibly of greater value than the direct beneficiaries. This could be captured in SROI. It will enable value to be attributed to the whole programme and would be cheaper to undertake requiring a lower level of ethical permission. Typically it would only need to be referred to a local university ethics committee. There are many practitioners of SROI the service would need to make sure it found someone who had been accredited to undertake SROI by Social Value UK or a local university researcher with health economic training. But the beauty of this approach is that it will valorise all the impacts identified in the logic model.

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Appendix A: Feedback questionnaire

Feedback Questionnaire for Forget Me Not Reminiscence Service

To help us provide a quality service to your clients and to assist us in applying for further grant funding please would you complete the following?

Please rate 1 as high/agree and 4 as low/disagree and if possible, give real life examples of any specific outcomes. Thank you

1. What did you hope the sessions would achieve?

2. How many of your residents have a Dementia diagnosis?

a) 100% b) More than 50% c) Less than 50%

3. After a session have you noticed any of the following? Mark 1 as high/agree 4 as low/disagree

- | | | | | |
|---|---|---|---|---|
| • Clients continue talking about the session to each other. | 1 | 2 | 3 | 4 |
| • Talk to their visitors about the session | 1 | 2 | 3 | 4 |
| • Staff and Clients talk to each other about the session. | 1 | 2 | 3 | 4 |
| • Clients have gained new information about each other. | 1 | 2 | 3 | 4 |

• Clients have made closer relationships with each other.	1	2	3	4
• Staff have heard new information about a client's life.	1	2	3	4

Please bring this to life with an example

4. Have the sessions made a difference to mood or behaviour?	1	2	3	4
• Sessions generally have a positive effect on people's mood.	1	2	3	4
• Sessions generally have no effect on people's mood.	1	2	3	4
• Sessions encourage quiet or shy people to communicate/ join in.	1	2	3	4
• Sessions are meaningful for residents with sensory impairments.	1	2	3	4
• Clients look forward to the next session.	1	2	3	4

Please give a real life example of how a person has benefitted?

5. How would it affect your clients if we could not continue this service?

6. One of our visits costs our service £60. If our funding reduces would you be prepared to pay an increased fee?

a) Yes we would pay the full cost.

b) Increase fee by £5 - £10

c) No we would not increase current fee

7. Any other comments or suggestions?

Thank you for helping.

Name of Group or Establishment..... Date.....

Please return this form to: gill.amos@edvsa.org.uk

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