
The Positive Contribution of Life Story Work to Individuals and Carers

Promoting and Embedding Best Practice

Life Story Steering Group

September 2009

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Introduction and Background

What is Life Story work?

The pastime of 'scrapbooking' - making photo albums and sharing memories - is a common, everyday activity, which many people do to celebrate birthdays and anniversaries. It is part of the 'remembering' practices we all engage in throughout our lives. The success of the TV programme '*Who do You Think You Are?*', where celebrities trace their family history, goes to show just how interested we are in knowing who we are and where we come from. Everyone has their own story, with their own journey to make and although the journey can throw up many shocks and surprises, it is almost always rewarding.

Life story work, in the context of NHS and social care services, has been used successfully as an intervention with a wide variety of people, including children (who are Looked After), people with learning disabilities, older people, people with a diagnosis of dementia, Parkinson's disease and with individuals who have suffered a stroke. It is a means of enabling an individual to put together material, in whatever format works best for them, about their family, work and community life to affirm their identity as an individual with a biography. The practice of life story work can be invaluable in the pursuit of person centred care, thereby promoting dignity and respect and ensuring that the person is central to the care or support process and is not just seen in the context of their diagnosis or condition.

The aim of Life Story work

Life Story work aims to improve the quality of life and wellbeing of people by enabling them to document and share their life story in whatever means is best for them. Examples include written script, photographs, computer file, memory boxes, audio tapes or DVD. It is their story and puts them firmly in the centre. It is a vehicle for purposeful and respectful communication between the individual concerned and staff who are working with them to provide personal care and support.

Policy Context

The pursuit of person centred care is a central theme in all current policies including:

- a. the transformation of social care and the personalisation agenda set out in *Putting People First*¹;
- b. ambition and competencies set out as part of **World Class Commissioning**;²
- c. *High Quality Care For All – NHS Next Stage Review*³, which sets out the direction of travel for NHS services in England and endorses more personalised approaches to the delivery of support and care to individuals;
- d. **The Dignity in Care Campaign**⁴ - aims to stimulate a national debate around dignity in care and create a care system where there is zero tolerance of abuse

¹ Putting People First: A shared vision and commitment to the transformation of Adult Social Care, Department of Health (2007)

² World Class Commissioning, Department of Health (2007)

³ High Quality Care for All – NHS Next Stage Review, Final Report, Department of Health (2008)

⁴ Dignity in Care Campaign, Department of Health (2006)

and disrespect of older people in particular. It is about changing the culture of care services and placing a greater emphasis on improving the quality of care and the experience of citizens using services including NHS hospitals, community services, care homes and home support services;

- e. ***NHS Constitution***⁵, which sets out the individual's and public's rights and the pledges from the NHS in response to these rights;
- f. ***Living Well with dementia – A National Dementia Strategy***, setting out the government's commitment to individuals with dementia and their family carers ensuring high quality care and support, based on individual need and enabling people to live well with the condition⁶;
- g. ***'Everybody's Business - Integrated mental health services for older adults: a service development guide'***⁷, which sets out what the components of a modern service should look like for older people with mental health needs;
- h. ***Improving services and support for older people with mental health problems***⁸, which is the second and final report of the UK Inquiry into Mental Health and Well-Being in Later Life. The Inquiry was launched in late 2003 as a result of concern that mental health in later life is a much neglected area. It published its first report, Promoting Mental Health and Well-Being in Later Life, in 2006. This final report sets out to answer how we can improve services and support for older people with mental health problems;
- i. ***End of Life Care Strategy***: Promoting high quality care for all adults at the end of life⁹
- j. the ***Independent Living Strategy***¹⁰ – a cross-government strategy for all disabled people;
- k. the Carers Strategy, ***Carers at the heart of 21st-century families and communities***¹¹;
- l. ***Aiming High for Disabled Children: transforming services for disabled children and their families***¹²;
- m. ***The Children's Plan: building brighter futures (2007)***¹³ and
- n. ***Valuing People Now – a new three-year strategy for people with learning disabilities***¹⁴

All of these policies focus on

- Individual led services, based on needs and preferences
- Putting the person in control and offering choice and
- A trained and competent workforce

⁵The National Health Service, Constitution, Department of Health (2008)

⁶Living Well with dementia – A National Dementia Strategy Department of Health (2009)

⁷Everybody's Business - Integrated mental health services for older adults: a service development guide CSIP (2005)

⁸Improving services and support for older people with mental health problems (2007) Age Concern

⁹End of Life Care Strategy: promoting high quality care for all adults at the end of Life, Department of Health (2008)

¹⁰Independent Living Strategy, Office for Disability Issues (2008)

¹¹Carers at the heart of 21st-century families and communities, Department of Health (2008)

¹²Aiming High for Disabled Children: Better Support for Families, HM Treasury/Department for Education and Skills (2007)

¹³The Children's Plan: building brighter futures. DCSF CM7280 (2007).

¹⁴Valuing People Now: a new three year strategy for people with learning disabilities

Life Story work helps to challenge ageist attitudes and assumptions. It can be used as a basis for individualised care and significantly improve assessments of need, assisting in the transitions that many individuals have to make in the course of the care journey, between different living environments (e.g. home to hospital, extra care, sheltered housing, extra care, care home or other care setting). During these transitions, life story work can help to initiate, develop and sustain better relationships between the individual person and staff who work with them and between family carers and paid staff.

Life story networking event in November 2008

The context

Whilst Life Story work began over 20 years ago and there are acknowledged areas of innovative practice, there is no single repository for sharing knowledge and best practice for individuals, families / carers or front line staff.

At the national faculty of old age psychology (PSIGE) 2008 annual conference in York, there was much interest in the symposium on “Life Stories – turning theory into practice, getting it into services”. It featured carer Ken Holt, who initiated the life story work steering group in Oldham in 2003 after he produced his wife’s life story as she was admitted to residential care. He explained, via a recorded interview, how he mobilised local agencies to work together to deliver a joint approach. When asked what his vision for the future of life story work was, he replied, without hesitation, that there should be a national network for all those people using Life Stories or developing such services to share experiences and learn from each other. This suggestion was warmly received and taken up by CSIP’s National Lead for Older People at the time.

With this leadership some initial resources were identified within the three northern regions - North West, North East and Yorkshire and Humberside - and small group of people met to explore the ways in which to take this work forward. Initial scoping work undertaken to look at existing good practice in this area generated a tremendous response, with many people asking to be further involved in any future work, the idea to host an event was born. The aim of the event was to raise awareness around the current Life Story work and illicit whether there was interest from across the disciplines in the proposal to develop a network on a more formal basis. The ‘Life Story Network’ event took place on 17th November 2008 and attracted over 80 delegates from across the northern regions.

Outcomes of the event

The feedback from the delegates was very enthusiastic and confirmed a focus on the following key areas in order to develop and sustain the valuable work encompassed by Life Stories:

1. Continue to gather and collate information on current activity around Life Stories;
2. Establish an electronic network;

3. Integrate the work and innovative practice on Life Stories into an existing relevant website and ensure integration with other associated websites;
4. Organise a national launch event.

Developing and sustaining Life Story Work

It was agreed at the event in November 2008 that a short-term steering group should be established to sponsor and guide the initial development and embedding of the proposed Life Story Network. The steering group met on 23rd January 2009 and began the process of scoping out its aims and terms of reference. The emerging Life Story Network governance arrangements are attached in Appendix A.

A Life Story Model

Whilst there is no one way to begin to develop life story work, a good starting point is that life story work is part of 'normal' everyday activities, which people enjoy.

However, family members, carers and staff often find it difficult to know where and how to begin the process of life story work for individuals who may have some cognitive impairment arising from illness, disability or injury. The model illustrated in the following diagram attempts to identify the relationships between networks and support structures and the development process for a good quality Life Story.

The central role is taken by the individual themselves. From that person extend the relationships, networks and support structures that may already be in place or are beginning to mobilise. Those relationships that surround the person are the care and support structures that can make a potentially significant difference to the person's life when fully engaged.

In the diagram, the lines connecting the person to the support networks demonstrate the different levels or strength of relationship and vary according to the ability to support the development of the Life Story.

Figure 1: A Model for Undertaking Life Story Work



- High likelihood of engagement and development
- Good likelihood of engagement and development
-** Reasonable likelihood of engagement and development
- . - . - .** Least likelihood of engagement and development

Carers & Relatives

This is denoted by a thick solid line which indicates the strongest relationship in relation to knowing and understanding the person's needs and hence in developing the person's Life Story. Wherever possible the individual, with their relatives, family carers and friends, should begin to develop their Life Story while they can remember the things that are important to them.

Primary Care

This includes GPs, Practice Nurses, District Nurses and Community Matrons. Life Stories might not begin here but there is a good likelihood that information can be sought and included. Primary care can provide health information though this may be more problematic because of confidentiality where the person does not have capacity to consent. This confirms the need to begin the Life Story as early as possible.

Community Links

Where the person is involved in community activities, they may be well known at the local leisure centre, community centre, faith group or library. These may provide good informal support at least initially. For example, the local church or faith connections will provide an insight into the activities the person is or has been involved in such as voluntary work, befriending or hospital visiting. This kind of information begins to build the picture of the individual.

Third Sector

Relationships with Third Sector groups such as Age Concern, MIND and Alzheimer's Society provide a reasonable source from which to develop the Life Story. There may be services provided to the person such as day care, silver surfers internet club or shopping. Voluntary sector staff may be the first to notice changes in memory or note confusion but may not feel concerned or confident enough to pass this information on. This may be due to the level of awareness and education of staff.

Acute Services

If the individual has a history of hospital admissions or out patient treatment, the acute sector may be able to provide information for the Life Story. Again, the issue of confidentiality and the capacity to consent will arise. The Acute Sector is one of the main environments where Life Story work would be of benefit. For example, a person admitted with dementia may have difficulty communicating their needs and wishes. Busy hospital staff could use the Life Story to understand better the needs and preferences of the patient and treat them accordingly. Many acute NHS trusts have embraced the Dignity in Care agenda and Life Story work fits well into that framework.

Care Home Sector

Staff working in residential care can support the individual and family carers in producing the Life Story, through their knowledge of the resident's likes and dislikes and their community networks. However, the care home sector often requires support to understand the value of Life Story work. There are some excellent examples of homes where varying forms of Life Stories have been used, but the culture of care may still remain that of "one size fits" all with insufficient attention to individual needs and preferences.

Capturing Innovative Practice

There are many examples of both how Life Story work is undertaken in many care settings and the benefits that individuals, families and carers have had from participating in this valuable work. The following are examples of the work from different perspectives.

Bolton Occupational Therapy, Greater Manchester West Mental Health NHS Foundation Trust

Over the last 2-3 years Life Story Work has developed within the Occupational Therapy team at Bolton. The OT team work in the in-patient wards, the community and an enhanced day centre.

We began by establishing an outline of questions/statements within the Life Story Books for use with service users and their carers. More recently we have made much use of our scanner to incorporate photographs and other memorabilia into the books. The books have enabled us to work with service users to stimulate both short and long-term memories. We have noted improvements in self-esteem and motivation. It has also been used as a method to improve communication between service users and staff. We have been able to assess aspects of cognitive functioning, behaviour, occupational functioning and mental state.

The benefits have been noted not only with service users but also with carers. At times carers may be confused, anxious or upset about what is happening to their loved one. The Life Story books have offered a means of positive communication and enabled the carers to interact with their loved one through the book.

More recently the life story work has moved on to include “getting to know you” questionnaires, memory books and boxes and even personalised placemats in our enhanced day centre. We strive to continue developing this area. We hope to share what we have done so far and also learn from other areas of good practice.

Amy Smith (Head Occupational Therapist – 01204 390118; E: Amy.Smith@rbh.nhs.uk)

Oldham life story work – embedding it into practice

Background

Ken Holt, a former carer and very active carer representative, completed a piece of life story work on behalf of his wife, Alice, for the staff in the residential home she was moving to in July 2003. As a way of helping the staff get to know his Alice Ken prepared a brief account of her life, including work and schooling, likes and dislikes, and medication. The residential home found this very valuable, and it was a productive piece of work for Ken too. He then consulted with other carers and representatives from a wide variety of statutory and voluntary agencies, (e.g. Age Concern, Social Services, Pennine Care Trust, the Primary Care Trust, and the Carers Forum.) to see if this was something that would be useful on a wider scale, especially where the person cared for needs any form of long-term care or has communication difficulties. He found that Life Story Work was going on in various service areas within Oldham. The Oldham Life Story Steering group was officially born in April 2004.

Aims

- To improve the quality of life and well being of older people.
- To work towards 'life story work' becoming integral to the care planning process for older people and their carers so as to improve the quality of care.
- To bring together agencies from Health, Social Services, the Voluntary and Independent Sector to develop a joint approach to the Life Story Work in Oldham to improve the quality of care for older people receiving health and social care services.

Main activities

- Delivery of life stories by Age Concern Volunteers to people in residential settings (see Box Below).
- Training for staff and carers with carers a main part of the delivery. (To date over 300 people have been trained with an average of 3 life story books being completed by half of all participants – this is an estimate of 450 life stories). A retired Pennine Care practice development facilitator, Chris Newton, in conjunction with a trainer from social services, Linda Green, began to train staff in using life stories.
- Research and evaluation to support further funding bids.
- Linking in with "making connections not assumptions" project – a BME sessional worker has been piloting the use of Life Story work in Urdu with older Pakistani women. This is being included in the training.

Achievements

In November 2005 the group won a "Pride of Oldham" award. It was then nominated for a Greater Manchester Strategic health Authority award. In 2006 not only did Oldham Life Stories win the Greater Manchester SHA Awards, it won the overall Chairman's prize "because it was a carer's idea, taken up by professionals". Then in November 2006 it won a Highly Commended National CSIP Positive Practice award.

Key outcomes

- Life story is a key objective for the local council
- It is a key action in the most recent older people's mental health strategy for Oldham
- It is on the recommendations of the health overview and scrutiny committee.
- Care Managers now ask for life stories to assist in care planning.
- It demonstrates the power of what can be achieved from bottom up ideas when people work together.

Learning points

- The importance of listening to carers.
- This is an ongoing process that needs the commitment of a core group of people to keep it going.
- Working together across statutory and voluntary sectors has been a vital ingredient in creating an identity and raising the profile of the work. Rather than people working in isolation the steering group has been able to harness some resources and raise the profile of positive work with this client group in Oldham.

(Polly Kaiser, polly.kaiser@nhs.net on behalf of Ken Holt (carer) Linda Green (Oldham Practice Development) Chris Newton (Retired Practice development nurse), Julie McBride (Age Concern Oldham) Keren Cohen (Lancaster University) Frank Kenyon (Alzheimer's Disease Society-Oldham) Tara Caira (Oldham Carers' Centre)

(For more info on training contact Linda Green at linda.green@oldham.gov.uk).

Benefits of Life Stories for Carers - a daughter's perspective

Dad was 84 and living alone with dementia when offered the opportunity via the Oldham Life Story Group to 'produce' his life story with Chris, then a trainee clinical psychologist. Although he was severely cognitively impaired he welcomed the opportunity to talk about his childhood and working life in particular. He relished showing his portfolio of drawings from his career to anyone who was interested as well his many watercolours. He talked about his many hobbies and love of outdoors so took Chris on his daily walk to show him.

Dad was very pleased to have someone interested in his life but said why me? I suggested that he'd had a very interesting life and other people might be interested in it. He clearly felt valued and proud of his 'book', so much so that he lent it to a friend at his weekly dance before it was even finished.

When Dad agreed to move to a permanent care home near me the book was used by all the care staff so that they got to know him quickly. This helped him to settle in to the home and for the staff to know his interests. He proudly showed his book to all the other residents too.

I continued to update the book, with Dad's permission and involvement.

The care home found this so useful that they asked other families if they could do life stories with all the residents.

From my perspective I was reassured to know that the staff had a lot of personal information about Dad and this helped them formulate and review his care plan. It reinforced for me that he was treated with respect and dignity as an individual.

At Dad's funeral the life story book was used to help the minister better understand Dad as a person. It is a lasting legacy for the family.

Jean Tottie E: jean.tottie@btinternet.com

Life Story project – Age Concern Oldham

The aim of the project was to recruit and train volunteers to spend time with an older person who may suffer from dementia to recall and write their life story. Once complete, the books should be used to support professionals and carers in the care of that individual as the person's likes, dislikes

and aspirations are included. These can then contribute towards the care plan, thus achieving more person centred care. In addition the books are used as memory aids for the resident, helping them to reminisce with family and friends.

The service has been running for over 4 years and has produced over 100 life story books for residents living in care homes in the Oldham borough. Volunteers are recruited and trained to spend time reminiscing with a resident, while taking notes which are later typed into a book using Publisher.

Families are asked to supply photographs relevant to their relative's life, which are scanned and incorporated into the book. Other images relevant to the text are found on the internet and used to make the life stories as full as possible. Each life story book is presented to the resident and their family on completion.

To produce life story books we have a team of typing volunteers who meet once a week. Many of our typists had very little knowledge of computers prior to beginning the project, so it has been necessary to train them. There is definitely a training element within the project. We have purchased seven computers for this purpose and sessions are held in a room at Age Concern Oldham's head office. The project relies heavily on the support of all our volunteers who give up to three hours of their time each week.

We are funded in part by Oldham PCT and by Age Concern Oldham.

The continued success of the project has enabled us to grow and recruit more volunteers (we now have 40), which in turn allows us to help more residents produce their life stories. We continually monitor the project through quarterly questionnaires which are sent to care homes, professional staff and families of those we have worked with. Any areas identified in these returns which can be improved on, are done so whenever possible.

We are looking at offering an alternative way of producing life stories to the resident, so they have a choice of which format they would prefer. We will also continue to recruit volunteers so that the service can produce as many life stories as possible for the residents of Oldham's care homes.

Contact: Lindsay Pateman, Life Story Project Worker, Age Concern Oldham T: 0161 633 0213

lifefiles.acoldham@btconnect.com

Preference Boxes - Age Concern Calderdale and Kirklees

The aim of this service is to enable older people and their carers to receive their chosen preferences. These will range from foods to ways of being cared for. It also aims for us to learn from each other and to share things that work and to be able to talk about worries and the losses that make Living with Dementia easy and less devastating.

Our approach to this work includes asking carers and older people living with Dementia to complete

details of their likes, dislikes and tastes in a variety of topics and activities. We then write these down and keep them in small boxes, which are individually decorated and used in Day Care and residential settings.

We are at the stage of collating these preferences and collecting suitable sized tins, that are small enough to hold information on laminated cards and can be kept close by. The materials used are mostly craft and textiles funded by clients and the copying is paid for by Age Concern. We use recycled objects. Our main costs are associated with paying for facilitators and we are presently relying on good will.

We hold our group in a community based centre as this is important in promoting a social model of disability rather than a medical model. Maintaining this 'social model' as a way of working when in partnership with NHS professionals can be a challenge.

The life story work has had a positive impact on members. They have become more confident and are attending Mental Health and carers' meetings which they did not go to or speak at previously. They have become more socially confident and are able to mix more easily at clubs and pubs and have gone away on holidays. They have told us that they have felt able to discuss their difficulties with everyday activities with fellow guests when staying in B/BS and generally feel less stigmatised about Living with Dementia.

We have been running the group almost 4 years and hope to continue but are dependent on funding for the facilitators wage from another charity, so 'good will' is a big factor in how successful we will be.

Contact: Eileen Rudden, Advocacy Officer, Age Concern Calderdale and Kirklees

The benefit of photographic memory diaries for orientation problems or memory lapses NHS Barnsley

The overall aim of this initiative is to reduce periods of disorientation relating to inability to recognise home and/or main carer and to reduce frequency and intensity of distress as a result of being unable to recall information relating to family members.

We work with individuals and carers to produce photographic memory diaries which chronicle the individual's life and focus on areas of orientation problem or memory lapse. We use both photographs and written text.

The project is funded primarily from petty cash for photograph albums. We also require staff time to collect information and formulate the memory diary; this has to be done alongside other duties. We make time to produce memory diaries and follow-up to monitor their effectiveness.

Other staff members have been trained to complete the process, however staff shortages continue to have an impact. Lack of time to supervise support staff carrying out this work is a challenge.

The impact of this work is measured by interviewing the individual and their carers for their views and feedback from carer on the effectiveness of the memory diary. Carer stress questionnaires

completed before and after were not found to be useful.

Memory diaries will continue to be used when a need is identified. This will be done by support staff.

Contact: The Senior Occupational Therapist, Occupational Therapy Department,

Portrait of a Life – Multi-Media Tool Kit

South West Yorkshire Partnership NHS Foundation Trust /The Mental Health Foundation.

Portrait of a Life - a multi-media toolkit for life story work is currently being developed by South West Yorkshire Partnership NHS Foundation Trust as part of a Collaborative project and in conjunction with the Mental Health Foundation. The Trust and Mental Health Foundation are developing the work and evaluating it with a view to it being adopted nationally. There is already significant interest from commissioners in the Yorkshire and Humber region.

The multi-media toolkit will support the knowledge and evidence base of staff working in a range of settings and organisations by providing them with an understanding of the rationale for life story work. The toolkit considers in some detail the risks and benefits, ethics and consent issues in developing life story work. It includes sections to support staff and people living with dementia to develop life stories and the practicalities of developing tangible products such as life story boards, memory boxes and electronic journals. It also considers the evaluation of life story work and shares the positive outcomes through individual case studies. It considers how the life story work supports care planning and purposeful activity to support quality of life, dignity and wellbeing.

The DVD demonstrates clearly the impact of life story work in relation to reminiscence activities.

The toolkit is underpinned by the CARER model which promotes positive engagement and partnership working with family carers and partners in care.

The toolkit is a practical resource containing two DVD's, a written guide book with PDF, which can be photocopied. The training DVD replicates the contents of the written guide with a menu of options whilst the other DVD 'Going Home' provides the perspective of a person living with dementia. The written guide and the training DVD are designed to be worked through systematically before returning to specific chapters or menu options for more detail.

The toolkit will be finalised in Autumn 2009. Further details can be obtained from andrea.trangmar@swyt.nhs.uk, who can also place you on a mailing list to receive regular updates.

Moving Forward - Next Steps

Life Story work is at an exciting phase of development. It is now clearly embedded in the Dignity in Care campaign and is highly relevant to other policy areas, including the National Dementia Strategy, New Horizons and the Carers Strategy. Life Story Work featured strongly in the annual report of Sir Michael Parkinson, Dignity Ambassador. The intention is to develop the resources initially accessible through the Dignity in Care web pages and establish an electronic network so that learning and ideas can be shared more widely. The National Mental Health Development Unit has agreed to host the Life Story Network

A short term secondment to complete this piece of work and plan a launch conference is has bee arranged.

The steering group established after the Network event in 2008 will continue to meet to oversee the work and report back to the DH Dignity policy lead.

Appendix A Governance Arrangements for the Life Story Network

Terms of reference

The following aims were discussed and subsequently agreed at a meeting of the Steering Group on July 10th 2009:

- To raise awareness of the concept of Life story work and its contribution to improving quality of life and wellbeing;
- To facilitate the understanding that 'Life Story work' becomes integral to the delivery of person centred care for individuals, which will ensure that people's dignity is respected.

In order to take forward the above aims, the Steering Group has identified and set out the following objectives:

1. Share good practice and expertise in the development of 'Life Story' work via a website available to care / support staff and the public;
2. Provide access to tools and products to assist the practice of undertaking Life story work;
3. Promote education and awareness of the development of the life story network via the website and related events;
4. Share the evaluation and effectiveness of existing training programmes from network members;
5. Explore and optimise opportunities to embed and sustain life story work in everyday practice;
6. Link with education & training commissioners & developers to build the practice of Life Stories in to competencies;
7. Link with Care Quality Commission to build the practice of Life Stories in to inspection & regulation regimes;
8. Bring together the NHS, Social Services, private, independent and voluntary sectors to develop a joint approach to the Life Story Work in the commissioning and provision of care for individuals and their carers;
9. Produce regular updates on the progress of the network and on general project development associated work.

Website hosting

Site hosting and technical assistance will be provided by NMHDU's contract with ITS-services.

Website management

Copy submitted for the website will be considered for suitability/accuracy and proof read by the web governance group before being uploaded to the site for publication by the website manager.

Content and layout will be informed by the use of google analytic data. Page visits, video views, document downloads and overall navigation patterns will be supplied to the web governance group as and when required.

Website Content Management:

A clear process and flow chart will be produced by the web governance group

The process will be published on the site alongside a request for content submission by site users.

In addition to the site pages, the governance group will consider the use of additional online social media, as and when required, to meet the emerging communication needs of the network.

National steering group membership

The membership of the 'core' steering group is:

Individual	Job Title & Organisation
Ruth Eley Chair	National Programme Lead (Delivery) – Older People and Dementia Policy Team, Department of Health E: Ruth.Eley@dh.gsi.gov.uk
Jean Tottie	Former carer. Member of Uniting Carers for Dementia E: jean.tottie@btinternet.com
Ken Holt	Former carer
Debbie Smith	North East Region – Older Adult Lead, Department of Health E: debbie.smith@dh.gsi.gov.uk
Sally Rogers	Yorkshire and Humber Improvement Partnership (YHIP) – Older Adult Lead Department of Health E: sally.rogers@yhip.org.uk
Veronica Brown	Dementia Strategy Lead, Yorkshire and Humber Improvement Partnership (YHIP) Department of Health E: veronicabrown.dsc@btinternet.com
Suzanne Wightman	Suzanne Wightman, Senior Manager – Practice Development, Kirklees Older Peoples Services, South West Yorkshire Mental Health Partnership NHS Foundation Trust.

	E: suzanne.wightman@swyt.nhs.uk
Anna Gaughan	Regional Dignity Lead – Northwest Joint Improvement Partnership (Independent Consultant) E: anna@annagaughan.co.uk
Steve Amos	Dementia Lead – North east region Department of Health E: steve.amos@dh.gsi.gov.uk
Polly Kaiser	Consultant Clinical Psychologist Pennine Care NHS Trust Oldham Life Story Group and National Lead – Mental Health in Later Life programme, National Mental Health Development Unit E: pollykaiser@f2s.com

Other people may be co-opted to join the Steering Group as required. In addition, other time-limited working groups may be commissioned as and when required to undertake specific focused areas of work by the Life Story Steering Group. The Chair may also invite appropriate representatives to attend the Steering Group in order to present specific information or present the outcomes from projects and pieces of work.

The members of the steering group will:

- Assist the Chair and the group by attending meetings and undertaking agreed tasks;
- Represent and be a point of contact for their organisation;
- Feedback information from meetings to colleagues within their own organisation;
- Send apologies to the chair if unable to attend a meeting;
- Notify the chair of any changes in contact details.

Reporting Arrangements/ Governance

The Steering Group will report to the DH policy lead for Dignity in Care.

Minutes

- The minutes of the meetings will be taken by the Project Co-ordinator
- The minutes will be sent to all members prior to each meeting and ratified at the next meeting

The agenda will be compiled by the Chair, in consultation with all members of the steering group

Action

Task	Lead	Timescales
Template	AG/SA/PK	Done
Website	RE	Done
Video	AG/DS/SW	Autumn 09
Report	AG/SA/PK	Done
Launch Event	SW	Feb 10
Core Presentation	PK	Done