INTRODUCTION TO THE PACK

This pack has been developed by the Told in South Yorkshire - Life Story Work and People with Dementia Advisory Group.

This group was formed in 2011 and comprises people with dementia, family carers, health and social care staff and University lecturers. Members of the group involved in the pack include: Lynsey Button; Brian Fairest; Sandra Galloway; Claire Jepson; Jane McKeown; Kath Rimmer; Tony Ryan; Michelle Wattam.

A piece of art work was created by people living with Dementia from Grenoside Grange Hospital and Darnall Dementia Group; this has become the logo for the Advisory Group.

• Although many people are enthusiastic about using Life Story Work, it can be difficult to get started
• People with dementia, family carers and health and social care staff who attended workshops on using Life Story Work requested some information
• We wish to bring together our knowledge, experiences and resources into one place that might be shared by others

The content of the pack was based on the findings from 8 focus groups and from conversations with people with dementia, family carers and care staff asking what their information needs were.
BACKGROUND TO LIFE STORY WORK

The use of Life Story Work was first described in the 1980s with children who were adopted or in care. It was used as a way of helping the child to confirm their identity and roots.

In the 1990s the use of Life Story Work was detailed with: people with learning disabilities; older people in care homes; older people in general hospitals and people with dementia. Since that time it has also been used with people with mental health needs and people receiving end of life care.
We describe the use of Life Story Work with people with dementia as:

- A way of communicating with a person (and their family carers) about their life
- Finding out what was important to the person in terms of their memories, experiences, life events, values and beliefs
- Recording that information in a way that is negotiated with the person (and their family carers)
- Using that information with the person in everyday communication and care activities
- An on-going process of discovery

The benefits of Life Story Work may include:

For the person living with dementia

- It can help them to feel proud of their life
- Make them feel listened to and valued
- Help them to feel that they are contributing
- Assist in triggering memories
- Can give the person a ‘voice’

“I was noticing her expressions ‘Oh yes it was me’ when other people comment ‘Oh was you a school teacher’ and ‘I didn’t know you ran a pub’ and ‘Yes it’s me’ and like shuffling her clothes to... very proud of what she did do.” OT assistant about a woman looking at her life story book.

For family carers

- Can help them to feel like they are doing something helpful
- Can help them to remember the person in the context of their whole life and not just since they had dementia
- Can help them to feel proud of their relative and their achievements

“It was nice to recapture some of those memories ... the fact that he is still the person that you married he looks slightly different, he may act differently but it’s still the person that you married so I think I needed that little jolt back as well.” Wife about her experience of Life Story Work with her husband.

For care staff

- It is enjoyable to work with a person with dementia (and their family carers) in this way
- It can help staff to appreciate the person with dementia in the context of their whole life
- It can help make connections between staff and the person with dementia
- It can help staff to understand the person better
- It can help to challenge negative views and assumptions about the person

“I don’t think I quite knew the depth of her character, when you listen to her life story it’s been very troubled and traumatic at times and yet she’s come out very balanced and non judgemental and I think it’s just made me inspired really by how she’s handled things.” Nurse manager about a woman she undertook Life Story Work with.
QUALITIES NEEDED BY THE PERSON GATHERING THE LIFE STORY

Life Story Work is not just about gathering information about a person’s life. What is important is the way in which the life story information is gathered. The qualities of the person gathering the Life Story Work information are essential for the person with dementia to feel valued and comfortable.
These following qualities are important:

• Being open minded
• Not judging what the person says or judging their values and beliefs
• Having a genuine interest in what older people have to say
• Being inquisitive and curious about the lives of other people, without appearing nosey
• Awareness of own feelings, emotions and responses
• Being able to appreciate and tune in to the feelings of other people
• Respecting and valuing the person and their story
• Responding in a sensitive way to any emotions
• Being appreciative about what we can learn from the stories of older people
• An ability to listen and convey attention to the story teller
• Being able to reflect and learn from past experiences

Life Story Work is best gathered when you already know something about the person with dementia and have started to develop rapport with them; however Life Story Work can also help develop and strengthen rapport with the person.
HOW TO GET STARTED

Getting started with Life Story Work can feel difficult, especially for the first time.

There can be an idea that there is a “right way of doing it” or it can feel like an overwhelming prospect. This is summed up by a staff member starting out with Life Story Work:

“Actually getting going is quite difficult … it’s one of those things you look at as quite a big thing and where do I start? Who do I ask? Where do I go to find out this information? Once you get going it’s kind of easy and you find your way and you find your paths.”

Our advice would be to ‘make a start’, ‘give it a try’ and ‘start small’ and hopefully this pack will guide you through the process.

This section is especially relevant to staff who are considering using Life Story Work with people with dementia.

A: Seeing if a person wants to participate in Life Story Work

Identify a person who you think may benefit from / enjoy Life Story Work

Talk to them about it and get an idea of whether they are interested or not. Notice their reactions, verbal and non-verbal. See if they seem to understand what is involved. Ask them if there are family members you can also talk to in order to keep them informed and also gather information from (be guided by the person’s wishes)

Consider a number of key questions to ask of the person and people who know them well:

• Has the person been someone happy to talk about their life to others?
• Are there any known distressing or unpleasant memories the person may prefer not to relive?
Do you think the person would like care staff to know more about their life to assist in their care?

Is the person someone who is happy to share their views and opinions with others if given the opportunity?

Getting formal 'consent' in a written form is not always necessary or relevant as you need to appreciate the person may change their mind at any point during the process. It is important though to note responses and respect the person’s wishes. Remember not everyone enjoys reminiscing.

B: Gathering Life Story Work information

Some people find having a list of questions or topic areas can help to provide some structure to gathering information. Examples of these can be found in the Resources section. The main advice is to start with what the person wants to tell you, be led by them rather than a list of questions. If you do start by using questions or topic areas you should find as your confidence increases you will rely on them less and less.

Aim to include the person with dementia as much as possible in telling their own story. Sometimes this can be difficult and you may also need to find other people and ways to find out about a person’s life story.

The person living with dementia

Through everyday conversation rather than using list to ask questions.

To fill in more details or gaps in information obtained from elsewhere.

To get the person’s own version of events.

Family / close friends

Check with the person with dementia that this is OK.

Ask what memories / stories / information the relatives / close friend have.

Perhaps leave a checklist such as “This is Me” for family members to complete.

Ask about any photographs / documentation that might add to the information (offer that these can be scanned, don't use original photos in any book as they may become lost or damaged).

Other staff

If the person with dementia is unable to offer information and/or has no family consider finding out what information other staff know about the person. Maybe ask them to complete a checklist such as “This is Me”, or talk to in handovers, on the phone, in team meetings.

Care notes

Work through care notes and medical notes.

Check accuracy of information with person or family where possible.

C: Recording the life story

The benefits of recording the person’s life story are:

• It can then be used with the person as part of their care and interactions
• It provides a record and a prompt if the person with dementia forgets part of their life story
• It can be shared with other people so that they can get to know the person better
• If a person moves between care settings the record can accompany them

The resource pack includes sections on different ways to record life stories and what to include. What does need to be considered is how to involve the person with dementia and family members in how to best record the life story and check they are happy with how it is recorded (checking content, typing errors etc). Make a record of who the person with dementia is happy to view their life story record and if there is anyone it should not be shared with.

Tips and hints for staff

• Appoint a person to co-ordinate the work
• Agree who is going to do what as individuals or in pairs
• Have a central place / box file to put photographs, stories / memories, snippets of information picked up in conversation
• Agree on a date for when all information is to be gathered
• Set a meeting after all information is gathered to agree how this will be used. Involve the person with dementia and any family
Life Story Work is generally a safe and enjoyable activity. It can help however to be aware of a few considerations so that you are prepared for any issues that may arise.

**Public versus Private stories**

Life Story Work is about helping a person to recount and celebrate the parts of their life that they choose to focus on. It is not about prying into people’s lives. However, very occasionally people might talk about private stories.
It can be helpful to view the information gathered in Life Story Work in terms of an analogy of a chest of drawers, first described by Professor Dawn Brooker.

**Top Drawer:** Information we would be happy to share with most people we meet, for example, names of family members, pets, where we grew up, what jobs we did, basic preferences, where we went on holiday.

**Middle Drawer:** Information we may choose to disclose in the context of a friendship or caring relationship and may include: thoughts, feelings, beliefs, significant relationships, more personal memories.

**Bottom Drawer:** Information that may be private to a person or perhaps a few close others and not for the public domain and may include: family secrets, private or traumatic memories.

Life Story Work should focus primarily on ‘top drawer’ information. We find that sometimes as relationships and trust build then people may speak about ‘middle drawer information’. ‘Bottom drawer’ information is not invited in life story work but occasionally is spoken about. If people with dementia divulge ‘bottom drawer’ information then this should not be included in any life story work record.

Who is the Life Story Work for?

Life Story Work should keep the person with dementia at the centre of the process. There is no doubt there are great benefits for family and friends and for care staff, but the story belongs to the person with dementia primarily.

Family and friends will have their own views on what stories should be told and what photographs should go into a life story book. These are important opinions but make sure the person with dementia remains in charge. It does not matter if stories are not accurate, it is what the person with dementia wants to tell. It may be that family and friends want to make their own version of a life story book.

“She was very definite about what she wanted in and what she didn’t want in. Her daughter had picked photographs that she had thought Eileen would want and quite a few of them weren’t what Eileen wanted at all…. so she very much collaborated, participated in and took the lead … which I thought was really nice, cos it wasn’t what I was expecting.” Nurse manager working with Eileen and her daughter.

Even if the person with dementia appears unable to contribute to their own story do everything you can to keep them involved. Notice their facial expressions to photographs, objects or accounts of their life. If you find out a snippet of information can you engage them in telling you more about it? Can they make choices on what book to choose, what to decorate their memory box with, can you work out which objects are their favourite, which textures or smells they prefer?

**Quality Checking**

It is important that the final Life Story Work record is of a good quality. Spellings should be checked and the quality should reflect the precious nature of the work. Having a final editing meeting with the person with dementia and family or friends can help.

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Helping a person to record their life story in some way can have a number of benefits.

- It can be used with the person in communication and care.
- It can be shared with other people that the person is happy for it to be shared with.
- It can accompany the person to new care environments, helping others to get to know the person more quickly.
- It can record memories that might otherwise get forgotten.

There are lots of different ways to record a life story and it is important to offer the person (and their family carers) the options and also think about how the life story will be used.

There is no right or wrong way and each person will want something different but it is worth spending time first thinking:

- Who will be using the life story record?
- Where will it be used and kept?
- Is the method you are thinking of using fit for the way it will be used?
Support worker Janice made a beautifully intricate and delicate life story book for Cynthia. Cynthia and her family loved it and it provided a wonderful testimony to Cynthia’s life and a precious keepsake. However, staff were worried about using it with Cynthia regularly in the nursing home fearing it would get damaged and it remained locked in the nursing office. A decision was made to make a more robust version that could be used on a daily basis with Cynthia, and her family took care of the more delicate version.

**Life Story Books**

Life story books can take many different forms but generally are a collection of photographs, text, maybe including certificates, maps, photos of mementos, stories.... here are some examples...

**TIP...**

People’s stories continue and it is good to leave space to add to a person’s life story with more recent photographs and accounts.

**Online Story Books**

A number of companies offer the opportunity to upload photographs and words to make a digital story book that is then printed and sent to the customer.

**Memory Board**

A cork board for example with photographs, mementos, images, words etc to reflect an aspect of someone’s life. Or perhaps a deep photograph frame with a Perspex covering to protect what is inside.

**Digital Photograph Frame**

Having a loop of photographs playing or perhaps just a couple of significant photographs that may be a talking point and a trigger for memories.

**Tablet Computer**

To store and display photos, the advantages being that you can zoom in on the detail of photographs that would otherwise remain small and maybe hard to see. The photographs can be kept on individual memory sticks if used in a care setting.

**A Memory Box**

A box decorated in things relevant to the person and containing mementos that trigger memories. This may also include more sensory objects that might evoke memories through touch or smell.

**Collage**

A large photograph frame mounted on a wall with a collection of photos and text, or a mixture of images, words, colours and textures created with paper or materials.

**Sounds**

A recording of sounds that are significant to the person and may evoke memories. For example scissors cutting through fabric may be significant to a seamstress; the sound of a lawnmower to a grounds man; the sound of seagulls may evoke holiday memories and stories.

**Web Pages / Social Media**

There are so many opportunities to create life stories through webpages, personal websites, social media sites, blogs. Clearly it is important to check who else might be able to view these and review privacy settings.

**A Film**

This could be a film of the person talking about their life, or might involve a selection of photographs and text perhaps set to a favourite piece of music.

**Case Study**

A group of older men from the Yemen living in the UK were approached about Life Story Work. Most did not have any photographs or mementos. A number were unable to read English or Arabic. A decision was made to film the men talking about their lives and this has resulted in very moving and insightful film that provides an understanding of their experiences and lives.
When recording a life story there are lots of different ways that you might want to complement the stories that people tell. What is important is that you focus on what the person wants to tell you. A life story does not have to be a chronological account of a person’s life.
Case Study

Brian did not want a complete account of his life – he wanted his life story book to start at the point he met his wife as he said that was when his life really began.

For some people their life story may be one photograph with some words on it that help trigger memories and conversations with the person; or it might be one significant object that the person can see and touch that prompt a story.

Some examples of what you might include:

• Episodes of life eg: work; being a mother/father; sports achievements; focus on a hobby; life since marriage; life after retirement; holidays
• Snippets of what the person wants to have recorded – no matter how small
• Important people
• Significant places
• Photographs (get them scanned rather than use originals)
• Maps
• Written accounts of a person’s memories
• Stories from others
• Certificates
• Photographs of mementos, artefacts personal to the person
• Objects of significance kept in a memory box
• Pictures from the internet relevant to the story
• Scanned cards or letters

Case Study

Gordon’s life story book included a hand written story and drawings from Matthew his Grandson about Granddad; how he was a great gardener, drawings of things he grew, memories of things they did together. It added a moving account to Gordon’s life story book, something that everyone who saw his book commented upon. It also encouraged Matthew to look at the book regularly with Gordon.

Case Study

Marion had very few photographs to include in a life story book. Marion’s son David searched the internet and found photographs of the street which she grew up on and the church she was married in. These became a trigger for memories for Marion.

TIP...

It can help to get small photographs enlarged so that the person can see the detail, which may otherwise be overlooked.
RESOURCES

Places and resources to consider

• Local library – particularly the local history section
• Local museums and more specialist museums such as the Yorkshire Mining Museum
• Yorkshire Film Archive
• Books and magazines of local history and specialist interests
• The internet generally for information, photographs and images (check any copyright)
Case Study

David works in a care home and described a resident Margaret, who was very withdrawn and uncommunicative. One day he was looking through a book of local history with her when she pointed out a picture which had her Father and Uncle in it. The memory triggered a long conversation. David took the book and got the picture enlarged and mounted and presented Margaret with the photograph. She was delighted and other residents showed an interest in Margaret and her stories about the photograph. This gave Margaret the confidence to begin coming to the dining room for meals and socialising with staff and residents. It’s amazing that such a chance sharing of a local history book lead to such a difference.

Equipment

Equipment will depend on the way the person’s life story gets recorded but some examples of resources/equipment you may need access to include:

- Scanner to scan photographs (photo shops often have these)
- Printer – preferably colour
- Computer
- Photograph frames of different sizes
- Photo paper
- Photograph albums, books

Possible Links and Resources to Life Story Work

Remember these will change so every so often use an internet search engine to check for new additions. We are not endorsing any of these site/links/resources; they are just ones we have found that might give people ideas:

www.pricelesstreasuresonline.com
www.activitiestoshare.co.uk/p/125/life-story-books
www.dementiauk.org/information-support/life-story-work/

Websites around Life Story Work and Storytelling

www.toldinsouthyorkshire.co.uk
www.lifestorynetwork.org.uk
www.storyingsheffield.com
www.makingwaves.org/life-story/
FREQUENTLY ASKED QUESTIONS

Is Life Story Work something everyone with dementia should take part in?

No, it is a personal choice. Many people with dementia and their family and friends find it really enjoyable and a good way to record and recall memories. However, not everyone enjoys reminiscing and it has to be up to the individual to decide.

Doesn't Life Story Work also bring up upsetting memories?

Life Story Work can be emotional for the person with dementia, for family carers and for care staff. However, feeling sad and emotional is a normal part of life and should not discourage people from using Life Story Work as generally the benefits outweigh the concerns. So long as the people concerned are given time to express their upset then it can be very helpful. Very occasionally Life Story Work can evoke more upsetting or traumatic memories, but in our experience this is quite rare and can often be minimised by finding out at the start if there are aspects of a person’s life they would prefer not to recount.
Can people with more advanced dementia benefit from Life Story Work?

Yes, you just need to be more creative in how you involve them and use Life Story Work with them. We have many examples where people with more advanced dementia seemed to respond to seeing photographs, hearing noises or from touch or aromas. You need to believe that the person can communicate and look for subtle signs in their body language, facial expressions and words. You might want to also work closely with family and friends to gather information. Sometimes a small snippet of information you know can evoke a response. Even if you don’t notice a response you can still talk to the person or engage in activities that you know were important to them.

Does the information the person tells you have to be ‘true’?

We all edit our stories depending who we are talking to. What the person with dementia tells you is their truth and it is important to accept and value their reality. Sometimes this can be difficult for family and friends who want the story to be accurate in their eyes. It is important to remember that the story belongs to the person with dementia and try and negotiate an understanding of that with family and friends.

Should everything the person tells me during Life Story Work go into their life story record?

It is important to check with the person what they want to go into any life story record and what they wish to remain private. Don’t underestimate the abilities of people with dementia in being able to be involved in this decision. If however you have concerns over their dignity or the confidentiality or dignity of family and friends then discuss with a trusted colleague. Occasionally you may have to decide to edit a person’s story to protect them or others. Use the ‘Chest of Drawers’ analogy to help guide you.

What if the person changes their mind and wants the life story book destroying?

Sometimes people willingly share their life story and agree for this to be recorded. Very occasionally the person may then change their mind. It is important to respect the wishes of the person; after all it is their life story book. It is perhaps wise to wait a while and bring up the subject again in case the person changes their mind back, but if the person is insistent then you have to respect their wishes and destroy their book.

How can I inform other colleagues about using Life Story Work?

Sometimes you might find that you work with a person to gather and record their life story book, but colleagues and other staff may not use it with the person. It may be that you need to inform everyone about the work, show them the life story record, explain the benefits, let them know how they can use Life Story Work with the person when you are not there. Maybe you could show them this pack, perhaps ask your manager for support. It can help if the use of Life Story Work gets written into the person’s care plan.
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