

Creating a 'life story' for a person with dementia



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sharing these with others helps them understand who we are as a person. A 'life story' is a record of someone's life that can be used to great effect for people with dementia.

How life story work can help people with dementia

People with dementia often experience problems with communication and memory. Life stories can be very beneficial in helping them recall important aspects of their life and communicate these to other people, creating opportunities for connection and interaction.

Compiling a life story can:

- help people with dementia share who they are and convey important information about themselves, their history, their likes and interests, and the things that matter to them
- enhance the person's sense of identity and give their life meaning

- encourage reminiscence, which can help them retrieve past memories
- bring a sense of enjoyment and contentment through thinking about happy times and the things that bring them pleasure
- help family members develop a closer bond with the person with dementia through sharing their stories
- give carers, care home staff, and health and social care professionals a better understanding of the person's life – this can help them provide better care, enable meaningful conversations and activities and make the person feel valued and respected

Even if the person with dementia has significant memory loss, a life story is a reminder that they are still the person they used to be, with a rich history and their own experiences, likes, dislikes and values. It can help you and others see the person behind their dementia.

What does life story work look like?

There are several ways of producing a life story, and you can choose the format – or combination of formats – that works best for the person with dementia.

Books: this format is portable and easily accessible to carers and visitors. Keep it simple with clear, easy-to-read text and photos. Different colours and patterns can be confusing for people with dementia, so stick to one font and size, and use no more than two contrasting colours.

It is a good idea to laminate the pages of the book to protect it from damage. Alternatively, you could compile the information inside punched pockets in a ring binder or print it as a photobook. You can also buy pre-formatted life story books to fill in, but these can be expensive and give you less flexibility over what you include.

Many care settings have their own life story book formats so you may need to transfer some of the information into their template as well. Collages or memory boards: these are less easy to adapt and add to as things change, but images often work well to encourage reminiscing and can be useful for people in the later stages of dementia who have difficulty reading.

As well as photos of important people, places and occasions, you can include other items such as postcards, pictures printed from the internet and newspaper or magazine clippings.

Video recordings: these are a good way to record visual and audio information such as family films, messages to and from the person with dementia, meaningful music and recordings of video calls. They also enable family and friends who the person doesn't see often to contribute – for example, relatives who live overseas.

You can add to the recording over time – for example if the person with dementia uncovers a new memory, or if another person wants to record a message for them.

My Life Films is a charity producing life story videos free of charge for people living in Greater London;

in many other areas, grants may be available, or there is the option to self-fund – please visit **mylifefilms.org**

Reminiscence or memory boxes:

these can be particularly useful for people with sensory impairments such as sight loss or perceptual problems, or for people in the later stages of dementia who rely more on touch or smell to communicate and connect.

Memory boxes can include a variety of items, such as jewellery, toys from the past, items of clothing, postcards, theatre or sports programmes, toiletries and ornaments – these may not be meaningful to others but can be very important to the person with dementia.

Apps: there are a number of apps that you can download to your phone or tablet so you can compile and save photos, videos and audio recordings. These are usually simple to use but may be more suitable for people in the earlier stages of dementia who are able to understand and use the technology, with support if necessary.

Personal profiles/one-page profiles: these are short versions of a life story containing a brief summary of the most important information about the person. They are often used in hospitals to help staff understand the person's needs.

How to create a life story

When creating a life story, involve the person with dementia in the process as much as you can, or as much as they want. It should reflect the person's wishes and preferences and encourage a sense of ownership. For example, let the person make a comment about a photograph and use their words as the caption – remember it is their story, not yours.

Help the person where necessary and compile the information together so they can see the story forming. Go with the flow and let the person talk about any aspect of their life that they want to. You don't have to start at the beginning or work in chronological order, and you don't have to include everything about their life – just what is most meaningful.

Try taking one topic at a time so the task doesn't become overwhelming. Take breaks and complete the story at the person's own pace; it might take days, weeks or months, and you can keep coming back to it to add new information.

If someone finds it difficult to communicate their life story, other family members and friends may be able to provide key information. You can also try to prompt them, for example by showing them photos or videos or playing familiar music, but bear in mind that there may be information about the person's life that you don't know about in detail.

Reflecting on our lives can be emotional, so be cautious and approach the activity with sensitivity. Some memories may make the person think about unhappy times and create a sense of loss or cause distress.

Don't be afraid of this, but think carefully about what information the person would want to share and when it may or may not be appropriate to do so. For example, you may wish to have one version



of the life story for family and close friends, and a second, briefer version to share with carers.

Life stories aren't just about the past – they also capture key information about the person with dementia at the present time. The life story can remain 'live' so you can keep adding to it to help other people better understand and relate to the person.

Always be led by the person with dementia when creating and using life story tools.

What to include in a life story

You may wish to include:

- the person's profile and basic information: name, date of birth, age, where they live etc
- significant relationships with family, friends, colleagues and pets
- their first language and other languages spoken
- religious, spiritual or cultural beliefs and routines
- their sexuality/sexual and gender preferences
- any physical or mental health conditions
- details of their childhood and education
- · details of their working life
- their achievements
- important places, eg places they have lived, places of study, holiday destinations, workplaces
- important life events such as weddings, birth of children or grandchildren, house moves, new jobs
- · preferences with their

- appearance, including what they like to wear, any religious or cultural dress, how they like to have their hair and make-up, jewellery, favourite toiletries etc
- food likes and dislikes, although be aware that these can change as dementia progresses
- present routines and routines from the past, even if they don't seem important now
- favourite music/TV/films
- activities they enjoy/don't enjoy, including sports and sports teams
- occasions that they like to celebrate eg birthdays, anniversaries, religious festivals
- values
- general likes and dislikes
- sad or traumatic life events, or things that would cause them worry or upset – it may not be helpful to revisit these with the person with dementia, but this information can help their family, friends and carers identify if changes in behaviour are linked to memories of a specific event.
 You may wish to keep this separate from the main life story

Try not to bombard the person with too many specific questions. It may be easier to ask more general questions or open up a conversation about a topic and let them direct the course it takes – for example, "Can you tell me about where you grew up?"

When the life story is completed, share it with family, friends and professional carers so they can get to know the person better and learn more about how to help them and meet their needs.

You may like to use Dementia UK's life story template. This is a flexible document, which can be adapted into a shorter or longer format with photos and pictures. You can download it at dementiauk.org/storytemplate

Sources of support

To speak to a specialist dementia nurse about life stories or any other aspect of dementia, please call our Helpline on **o8oo 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit **dementiauk.org/book-a-clinic-appointment**

Changing relationships and roles dementiauk.org/changingrelationships-and-roles

Tips for better communication dementiauk.org/better-communication

When someone stops recognising you dementiauk.org/things-to-try-when-someone-with-dementia-stops-recognising-you

Music therapy dementiauk.org/music

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email **feedback@dementiauk.org**

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Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.

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