

Life Stories Services Questionnaire Final

Q1 Life Story Work in Dementia Care

Q2 Survey of Services Provided for People with Dementia

Q3 Thank you for taking the time to complete this questionnaire. We are interested in your service, whether it uses Life Story Work and, if so, how it does this. Even if `{e://Field/NameOfService}` does not use Life Story Work currently, we are interested in your answers. Please remember that participation is optional. The answers you give will be kept secure and confidential and data will be anonymous. Findings will be used only to inform the research project about Life Story Work. The questionnaire usually takes around 15 minutes to complete, but could take less or more time, depending on how much you have to say. Most of the questions have tick box answers. You do not have to complete the whole questionnaire in one session: you can close the page at any time and your answers will save automatically. You can come back to the page and add more answers for up to a week after starting the questionnaire, as long as you are on the same computer. You can also move backwards and forwards between the pages. If you are happy to continue please click on 'Next page' below to start the questionnaire.

Q4 What do we mean by 'Life Story Work'? When we say 'Life Story Work', we mean: making something that records aspects of the life of a person with dementia, including their past life, their present interests, and their future wishes, hopes and dreams AND using these records to improve things (for example, care, relationships) for the person with dementia and those around them. The record of the life story can be a book, a box, a collage, on a computer or in any other format that the person wants. Some people may have several different types of record of their life story, for example a photo album, a collage on the wall, and a written record for care staff. We are interested in all types of Life Story Work. We are also interested in hearing about services that do not do Life Story Work or have never come across it.

Q5 Have you ever heard of Life Story Work for people with dementia?

- Yes (1)
- No (2)

If No Is Selected, Then Skip To Would like to know more about LSW (all)

Q6 Does $\{e://Field/NameOfService\}$ do Life Story Work with people with dementia currently?

- Yes, do Life Story Work currently (1)
- Have done Life Story Work in the past, but not now (2)
- No, have never done Life Story Work (3)
- No, but we refer on to another place or service where Life Story Work is done (4)

If Yes, do life story work cur... Is Selected, Then Skip To End of Block

Answer If Types of record A written summary Is Selected

Q7 Please write in the name and contact details of the place or service where you refer people to

Answer If Service ever done life story work (current) Have done life story work in the past, but not now Is Selected Or Service ever done life story work (current) No, have never done life story work Is Selected

Q8 People have different views about how helpful it is to do Life Story Work. Do you think Life Story Work could help the people who use $\{e://Field/NameOfService\}$?

- Yes (1)
- No (2)
- Don't know (3)

Answer If Service ever done life story work Have done life story work in the past, but not now Is Selected Or Service ever done life story work No, have never done life story work Is Selected

Q9 Why do you think that? (Please write in below)

Q10 Would you like to know more about Life Story Work?

- Yes (1)
- No (2)

Q12 People with dementia can do Life Story Work at different times. How soon after a person with dementia comes to \${e://Field/NameOfService} do you start doing Life Story Work with them?

- Immediately (1)
- Within a month (2)
- Between one and three months after they come to \${e://Field/NameOfService} (3)
- More than three months after they come to \${e://Field/NameOfService} (4)
- It depends (please give details below) (5) _____

Q13 A person's life story can be recorded in different ways. What kind of record(s) of a life story do you create in \${e://Field/NameOfService} with people with dementia? (please tick all that apply)

- A photo album just containing photographs (1)
- A photo album with written comments or stories (2)
- A book with a mixture of photos and stories (3)
- A written summary (4)
- A box containing important objects or memories (5)
- A collage to put up on a wall (6)
- A DVD or film (7)
- A poem (8)
- Something else (please give details below) (9) _____

Q14 Life Story Work can be done in different ways, for example, in a group or one-to-one. In what ways do you do Life Story Work in \${e://Field/NameOfService} when working with people with dementia? (please tick all that apply)

- In a group (1)
- One-to-one (2)
- Other (please give details below) (3) _____

Q15 Different people can be involved in doing Life Story Work. Who is involved in doing Life Story Work with people with dementia in \${e://Field/NameOfService}? (please tick all that apply)

- The person with dementia (1)
- Family members or others close to the person with dementia (3)
- A volunteer who does Life Story Work (7)
- A person/people employed specifically to do Life Story Work (5)
- A person/people employed to provide care more generally (6)
- Someone else (please give details below) (8) _____

Q16 People have different ideas about what life stories can be used for. Thinking about all the types of life story records that people with dementia in your service have, how is their life story used? (please tick all that apply)

	In \${e://Field/NameOfService}
	we use life stories (1)
To help the person with dementia remember important parts of their life (1)	<input type="checkbox"/>
To give the person with dementia pleasure when they look at it (2)	<input type="checkbox"/>
To help soothe or calm the person with dementia (3)	<input type="checkbox"/>
To help staff see the person behind the dementia (4)	<input type="checkbox"/>
As something for staff and people with dementia to enjoy looking at together (5)	<input type="checkbox"/>
As something for people with dementia to enjoy looking at with family members or other people close to them (6)	<input type="checkbox"/>
So that health or social care workers in other places or services can provide better care (7)	<input type="checkbox"/>
For other reasons (8)	<input type="checkbox"/>

Answer If How LSW used For other reasons - In \${e://Field/NameOfService} - we use life stories Is Selected

Q17 What other ways do you use life story records? (please write in below)

Answer If How LSW used To help the person with dementia remember important parts of their life - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used To give the person with dementia pleasure when they look at it - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used To help soothe or calm the person with dementia - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used To help staff see the person behind the dementia - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used As something for staff and people with dementia to enjoy looking at together - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used As something for people with dementia to enjoy looking at with family members or other people close to them - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used So that health or

social care workers in other places or services can provide better care - In $\{e://Field/NameOfService\}$ we use life stories - Use of life story Is Selected

Q18 You said that these were the different ways that you used life stories in your service. Please choose the one that you think is the most important (please tick ONE)

Q19 Different sorts of information or clues about a person's life can be included in a life story. These next four questions are about the different types of information that can be used to create a life story. For each question, please tick the answers closest to what you do in $\{e://Field/NameOfService\}$.

Q20 Thinking about all the types of life story records that people with dementia have in $\{e://Field/NameOfService\}$, what information is included about family and other people who are close to them?

	We always include this information in the life story (4)	We sometimes include this information in the life story (5)	We do not include this information in the life story (6)
The names of family members and other people close to them (31)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Details about or descriptions of family members and other people close to them (32)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their reactions to family members and other people close to them (33)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anything else about family or other close people (please write in - the box will expand as you write) (34)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q21 And what information is included about the person's life?

	We always include this information in the life story (1)	We sometimes include this information in the life story (2)	We do not include this information in the life story (3)
A list of important events, dates, places or stages in their life (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Details about important events, dates, places or stages in their life (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their feelings about important events, dates, places or stages in their life (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anything else about the person's life? (please write in - the box will expand as you write) (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 And what information is included about the likes and dislikes and preferences of the person with dementia?

	We always include this information in the life story (1)	We sometimes include this information in the life story (2)	We never include this information in the life story (3)
What they like to eat (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What they like to wear (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What they like doing (interests, hobbies, activities) (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Things they like to talk about (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Things they do not like to talk about (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anything else about their likes and dislikes? (please write in - the box will expand as you write) (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 And finally in this section, thinking about all the types of life story records that people with dementia have, what information is included about their needs?

	We always include this information in the life story (1)	We sometimes include this information in the life story (2)	We never include this information in the life story (3)
Medical or care information (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual and cultural needs or preferences (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any other information about their needs (please write in - the box will expand as you write) (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 Sometimes certain information about the person with dementia, or a particular time in their life is left out of their life story. Does this happen when people with dementia do their life stories in your service? (please tick one)

- Yes (1)
- No (2)
- Don't know (3)

If No Is Selected, Then Skip To One-off or things added
If Don't know Is Selected, Then Skip To One-off or things added

Q25 Why are certain things left out of life stories? (please tick all that apply)

- Some things are too private to include (2)
- Some things are too upsetting to include (3)
- Any other reason (please give details below) (4) _____

Q26 Who makes the decision to leave certain things out of the life story? (please tick all that apply)

- The person with dementia (1)
- A family member, or someone close to the person with dementia (3)
- A volunteer who does life story work (7)
- A person/people employed specifically to do life story work (6)
- A person/people employed to provide care more generally (4)
- Someone else (please write in this person's job title) (5) _____

Q27 Doing a life story can be a one-off event or it can be something that is added to as new memories come to light or new events take place. How would you describe Life Story Work for people with dementia in $\{e://Field/NameOfService\}$?

- It is a one-off thing and nothing is added to it once it is finished (1)
- Photos, descriptions, or other items about the past are added along the way (2)
- Photos, descriptions or other items about recent events are added as they happen (3)

Q28 Life stories can be about the past, the present and the future. Thinking about all the types of life story record that people living with dementia in $\{e://Field/NameOfService\}$ have, how would you describe these life stories? (please tick all that apply)

	Always (18)	Very Often (19)	Occasionally (20)	Never (21)
The life stories include general information about the past that are not specific to the individual person (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The life stories include memories and information about the person's past (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The life stories include current information about the person (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The life stories include the person's hopes and views about the future (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q29 People have different views about who should be able to look at a person's life story. Who is able to look at the life story of a person with dementia in *{e://Field/NameOfService}*? (please tick all that apply)

- The person with dementia (1)
- Family members, friends and people close to the person with dementia (3)
- Some selected staff who work here (4)
- Any staff who work here (5)
- Health or social care staff who work elsewhere (7)
- Others (please give details below) (6) _____

Q30 Do you ask the person with dementia to give their permission about which people can look at their life story? (please tick one)

- Yes, always (1)
- Sometimes (4)
- No (2)
- Don't know (3)

Answer If Does person give permission who can look at LS No Is Selected Or Does person give permission who can look at LS Sometimes Is Selected

Q31 In what circumstances would the person with dementia NOT be asked to give their permission about which people can look at their life story? Please write your answer here.

Q32 Do family members or others close to the person with dementia give their permission about which people can look at the life story of the person? (please tick one)

- Yes, always when there is a family member/other close person to ask (1)
- Yes, sometimes when there is a family member/other close person to ask (4)
- No (2)
- Don't know (3)

Answer If Have you given permission who can look at LS No Is Selected Or Have you given permission who can look at LS Yes, sometimes when there is a family member/other close person to ask Is Selected

Q33 In what circumstances would family members or others close to the person with dementia NOT be asked to give their permission about which people can look at the life story? Please write your answer here.

Q34 Does the life story of the person with dementia have a statement in it that says in what circumstances other people can look at it? (please tick one)

- Yes, always (1)
- Sometimes (4)
- No (2)
- Don't know (3)

Q35 Where is the life story usually kept? (please tick all that apply)

- The person with dementia keeps it (1)
- A family member or someone close to the person with dementia keeps it (7)
- In an office or other secure place in your service (2)
- In the care record of the person living with dementia (3)
- On display (please write in where) (5) _____
- Somewhere else (please write in where) (6) _____

Q36 How often do people normally look at or use the life story? (please tick one box in each row below)

	How often does this person use or look at the life story?						
	Every day (1)	A few times a week (2)	A few times a month (3)	Less than once a month (4)	Never (5)	Don't know (6)	Not applicable (7)
The person with dementia (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family or other people close to the person with dementia (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff who work in $\{e://Field/NameOfService\}$ (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Volunteers who work in $\{e://Field/NameOfService\}$ (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health or social care staff who work somewhere else (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other people (please give details) (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q37 This section is about your policies and practice for Life Story Work.

Q38 Below are some statements about policies and practice in {e://Field/NameOfService}. Please tick the answer closest to what happens in your service.

	No (16)	Yes (17)
We offer everyone the opportunity to do Life Story Work, no matter how severe their dementia (1)	<input type="radio"/>	<input type="radio"/>
Staff/volunteers who do Life Story Work do their own life story before they work with service users (2)	<input type="radio"/>	<input type="radio"/>
We use a template to guide Life Story Work from start to finish (3)	<input type="radio"/>	<input type="radio"/>
Staff/volunteers doing Life Story Work learn to do it 'on the job' rather than through special training (4)	<input type="radio"/>	<input type="radio"/>
Staff/volunteers doing Life Story Work get regular supervision from senior or more experienced staff (5)	<input type="radio"/>	<input type="radio"/>
Decisions about the format and look of the life story are made mainly by staff/volunteers who do the Life Story Work (6)	<input type="radio"/>	<input type="radio"/>
People with dementia who also have a visual impairment are offered the opportunity to do Life Story Work (7)	<input type="radio"/>	<input type="radio"/>
We train family members or other people close to the person with dementia before they do Life Story Work (8)	<input type="radio"/>	<input type="radio"/>
Everyone who works or volunteers in my service knows what Life Story work is (9)	<input type="radio"/>	<input type="radio"/>
Everyone who works or volunteers in my service	<input type="radio"/>	<input type="radio"/>

knows how to use a life story to improve the care of the person with dementia
(10)

We adjust how we do Life Story Work, depending on the needs and strengths of the person with dementia
(11)



Q39 Below are some statements about the time and resources that are available for Life Story Work. Please tick the answer closest to what happens in [\[NameOfService\]](#).

	Strongly Agree (22)	Agree (23)	Disagree (24)	Strongly Disagree (25)
Life Story Work is done in spare moments in the care routine (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The time spent doing Life Story Work makes it difficult to get other care work done (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
We have dedicated and protected time for doing Life Story Work (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Senior staff in the service are fully committed to Life Story Work being done (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any member of staff who wants to do Life Story Work with a person with dementia will have time freed up from other duties (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q40 Have there been any problems with doing Life Story Work with people with dementia in \${e://Field/NameOfService}?

Q41 What have been the best things about doing Life Story Work with people with dementia in \${e://Field/NameOfService}?

Q42 Is there anything else you would like to tell us about Life Story Work for people with dementia?

Q43 About your service It helps us to understand answers if we know a bit about the service you are telling us about.

Q44 What type of service does \${e://Field/NameOfService} provide? (please tick one)

- Memory clinic/memory assessment service based in an out-patient setting (1)
- In-patient dementia mental health assessment unit (3)
- Community care provider providing services to people with dementia (4)
- Specialist dementia care nursing or residential care home (2)
- Non-specialist nursing or residential care home providing care to people living with dementia (5)
- Other, please write in (6) _____

Answer If What type of service does \${e://Field/NameOfService} provide? (please tick one) Memory clinic/memory assessment service based in an out-patient setting Is Selected Or What type of service does \${e://Field/NameOfService} provide? (please tick one) Community care provider providing services to people with dementia Is Selected Or What type of service does \${e://Field/NameOfService} provide? (please tick one) Other, please write in Is Selected

Q45 Typically, how many people with dementia does \${e://Field/NameOfService} see each week? (write number in box)

- 1-10 (1)
- 11-20 (2)
- 21-30 (3)
- 31-40 (4)
- 41-50 (5)
- 51-60 (6)
- More than 60 (please write in number) (7) _____

Answer If On average, how many people with dementia live in your nursing or residential care home? (please write in number) Is Selected Or On average, how many people with dementia live in your nursing or residential care home? (please write in number) Is Selected

Q46 Typically, how many people with dementia live in \${e://Field/NameOfService}? (write number in box)

- 1-10 (1)
- 11-20 (2)
- 21-30 (3)
- 31-40 (4)
- 41-50 (5)
- 51-60 (6)
- More than 60 (please write in number) (7) _____

Answer If What type of service does \${e://Field/NameOfService} provide? (please tick one) In-patient dementia mental health assessment unit Is Selected

Q57 Typically, how many people with dementia are in-patients in \${e://Field/NameOfService} each week? (write number in box)

- 1-10 (1)
- 11-20 (2)
- 21-30 (3)
- 31-40 (4)
- 41-50 (5)
- 51-60 (6)
- More than 60 (please write in number) (7) _____

Q47 About youIt helps us to analyze our survey results if we know a bit about you. This final section asks for some simple personal details. If you would rather not give any of this information, please just skip the question(s).

Q48 What is your sex?

- Male (1)
- Female (2)

Q49 Which of the following age bands do you fit into?

- 16-24 (1)
- 25-34 (2)
- 35-44 (3)
- 45-54 (4)
- 55-64 (5)
- 65 or over (6)

Q50 What is your ethnic group? Please choose one option that best describes your ethnic group or background.

- White (1)
- Mixed / Multiple ethnic groups (2)
- Asian / Asian British (3)
- Black / African / Caribbean / Black British (4)
- Other ethnic group (5)

Q51 What is your job title?

Answer If Service ever done life story work Yes, do Life Story Work currently Is Selected Or Service ever done life story work Have done Life Story Work in the past, but not now Is Selected Or Service ever done life story work No, but we refer on to another place or service where Life Story Work is done Is Selected

Q52 You can find more about Life Story Work training and resources by visiting the Life Story Network website. The link to the website will be in the 'thank you' email that we will send you.

Answer If Service ever done life story work No, have never done Life Story Work Is Selected And Would like to know more about LSW Yes Is Selected

Q53 You can find out more about Life Story Work by visiting the Life Story Network website. The link to the website will be in the 'thank you' email that we will send you.

Q54 When you are happy with all your answers, please click ''Next page'' to submit your response. Once you have done this you will not be able to return to the questionnaire.

Q55 Thank you for helping us with our research. If you would like to receive a summary of our findings later this year, please tick the box below.

- I would like to receive a summary of the findings (1)