

Welcome!

We are from University College London and the Universities of Bradford, Northampton and Surrey. We are inviting you to take part in a research study. This research study is called the ANGELA Project and is dedicated to Angela, a lady with young onset dementia who went undiagnosed for three years before her symptoms were recognised.

This information will help you to understand what this project is about and how you might take part.

- Part A will explain the purpose of this study and what will happen if you take part.
- Part B will give you more information about the way the research will be carried out.
- Part C provides contact details and what to do if you want to take part.

If you would prefer to listen to this explanation, please visit the following link: <https://www.youtube.com/watch?v=j-uU24Bp8ZA&feature=youtu.be>.

Part A

What is the purpose of the ANGELA Project?

- In this project we seek to understand how to improve support for younger people with dementia and families/supporters.
 - We would like to learn more about your positive experiences of support and those of family members/supporters, during and after diagnosis.
 - We would also like to know which services you have used and a bit of information about yourself.
 - This information will be used to help others develop the forms of help and assistance needed by younger people with dementia and their families/supporters.
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Why is this research needed?

- Younger people and family members/supporters affected by dementia have special needs that are currently not met by the majority of services in the UK.
 - We are carrying out this research because of the lack of services and we need your expertise and experience to help younger people with dementia and their families/supporters.
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What does taking part involve?

If you agree to take part, you will be asked to complete a questionnaire on your computer or on paper. If you would prefer, we can arrange to complete it with you over the telephone or by Skype.

If you are living with a diagnosis of young onset dementia, you may find it helpful to work together with a family member/supporter to complete the questionnaire. If you choose to complete the questionnaire by telephone or Skype, the interview will be audio-recorded.

Do I have to take part in the study?

No, you do not have to take part. If you choose to take part but then decide to stop, **this will not affect the help and support you receive.**

Consent

If you decide to complete the questionnaire, you will be giving your consent to take part in the research. If you opt for a telephone or Skype interview, the researcher will check that you understand what you are being asked to do and are happy to take part.

What will happen to the information I give?

All the information you give us will remain confidential. No one will be able to identify that you took part in the study.

Part B

What is the ANGELA Project?

The ANGELA project aims to provide guidance to improve support for younger people with dementia and their families during and following diagnosis. It is a three year partnership between four Universities. The four Universities are:

- University College London (Leading Partner),
- the University of Bradford,
- the University of Northampton,
- the University of Surrey.

The project is funded by a grant from the Alzheimer's Society and external collaborators include YoungDementia UK and Dementia UK.

What do we mean by young onset dementia?

Young onset dementia is any form of dementia that is diagnosed before the age of 65.

What does taking part involve?

Taking part will involve completing a questionnaire. You can complete this on your computer or on a paper copy. If you prefer, we can arrange to complete it with you over the telephone or by Skype.

We would like younger people living with dementia and family members/supporters to give us:

1. Information on useful experiences of help and assistance you have received.
2. Information on the kind of services you have used and how often.
3. Some information about the area you live in and about your care.

If you are living with a diagnosis of young onset dementia, you may find it helpful to work together with a family member/supporter to complete the questionnaire. If you choose to complete the questionnaire by telephone or Skype, the interview will be audio-recorded.

What are the benefits of taking part?

Although we cannot promise that you will benefit from this project, we need your expertise and experience to help younger people with dementia and their families/supporters in the future.

What are the possible disadvantages and risks of taking part?

- Although we are focusing on positive experiences, some people may find it difficult to reflect upon the support they have received.
 - If at any time you feel upset, you can stop and take your time to decide whether you want to go on or withdraw from the research.
 - Information about sources of support for people living with dementia and their families/supporters will be available to everyone.
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What will happen to the information I give?

- All the information you give us will remain confidential.
 - No one will be able to identify that you took part in the study.
 - The information you give may be looked at by individuals or researchers from UCL and the Universities of Bradford, Surrey and Northampton or from regulatory authorities, where it is relevant to your taking part.
 - Reports on the study will not contain any information that would make it possible to identify you.
 - Personal data will be kept for 12 months while anonymous study data will be kept for 5 years after the end of the study.
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What will the information be used for?

The goal of the ANGELA project is to improve the support that younger people with dementia and their families receive during and after diagnosis.

At the end of the project, a report will be produced for those who develop services for younger people with dementia and family members / supporters including:

- Commissioners and Service Providers.
- The Alzheimer's Society and YoungDementia UK.

We will also publicise our findings with those involved in providing services and support in the following ways:

- A meeting which will present the results of the research.
- Leaflets with examples of good practice.
- Articles in journals.
- Presentations at conferences.
- Publications on websites including the Angela project website, YoungDementia UK and the Alzheimer's Society.

Part C

People to contact

If you require assistance or clarifications about any aspect of this research, please contact one of the Bradford-based researchers listed below:

Vasileios Stamou, V.Stamou@bradford.ac.uk, tel: 01274 233 994 or

Jenny La Fontaine, J.Lafontaine@bradford.ac.uk

School of Health Studies, Horton A Building, University of Bradford, Richmond Road, Bradford, BD7 1DP, UK.

Should you wish to receive independent confidential advice about taking part in research, please contact **Tamsin Holt**, Head of Research Support, Research & Knowledge Transfer Support, Richmond Building, Richmond Road, Bradford BD7 1DP, Tel. 01274 235 184, email: T.L.Holt@bradford.ac.uk

Complaints

If you would like to raise a concern with an independent person or to make a formal complaint, you can contact **Irvine Muronzi**, Havering Assistant Director for Adults Mental Health, NELFT Patient Advice and Liaison Service, Tel.: 0300 555 1201 (extension 66103), email: Irvine.Muronzi@nelft.nhs.uk

What next?

If you are willing to take part please continue to the questionnaires.

If you are living with young onset dementia, you may find it easier to complete this survey with a family member/supporter. If this isn't possible, you can ask one of the researchers to help you by contacting us, using the details above. Should you find it difficult to answer some of the questions it is acceptable for a family member/supporter to answer for you.

This study was reviewed and approved by the Health Research Authority on the 31st of July 2017.