

Survey to help improve palliative and end of life care

Do you have questions about palliative and end of life care, support and treatment? If you do please fill out this survey.

Why we need your help:

We are asking for your help because we want to improve care, support and treatment for people in the last few years of their lives. We know that many people have important questions about care, support and treatment, and we want to find out what they are. We want to use these questions to set priorities for research that will improve care for people at the end of their lives and their families and carers in the future.

Who you are:

- A person with a long-term illness who might be in the last few years of life
- Caring for a loved one or someone you know in the last few years of life
- A bereaved carer or family member
- A health or social care professional or volunteer working with people who are in the last few years of life
- A member of the public who has an interest in care for people at the end of their lives

Your experience and knowledge, as someone who has been directly affected by end of life care, will help us identify the most important questions that need to be researched.

What we are asking you to do:

Please think about your own experiences of care, support and treatment and fill in our quick and simple survey over the page. It should take you about 10 minutes to complete. You can do the survey on paper and post it back to us free of charge. Or you can complete it online or over the phone.

This is a unique opportunity to directly influence future research into care, support and treatment for people in the last few years of their lives.

What will happen to your question(s):

All the question(s) we get from everyone who takes part in this survey will be gathered together.

- The questions that we haven't yet got the answers to will be published (see overleaf for more information).
- We will bring together groups of patients, carers, family members, doctors, nurses and other healthcare professionals to look at these questions and identify the most important ones. You can be involved in this, if you like.
- This will result in a 'top 10' list of research topics which we will use to influence future decisions about research. For example it could help decide which research projects should get funding.

The online survey is accessible via our website palliativecarepsp.org.uk

What we mean by palliative care:

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For patients, palliative care includes management of pain and other symptoms and provision of psychological, emotional, social, spiritual and practical support.

For family, friends and carers it includes the support that can be provided to help the family cope during the person's illness and in their own bereavement.

Besides helping those approaching the end of life to live as well as possible until they die, palliative care is about supporting everyone involved in a person's life, such as family, friends and carers.

Palliative and end of life care
Priority Setting Partnership

SUPPORTED AND GUIDED BY



IN PARTNERSHIP WITH



Survey – section 1:

Your question(s) about palliative and end of life care

Your question(s) can be about anything that you think is important that went unanswered for you. All you need to do is write a sentence or two about whatever it is. If a question relates to any particular condition or disease, please tell us which one. Send us as many questions as you like. If you run out of room you can add an additional sheet of paper with your survey or fill the survey in online.

What question(s) do you have about **care, support and treatment** for people who are in the last few years of their lives that could help them to live as well as possible? This could also include question(s) about care and support for current carers or families.

What question(s) do you have about **care, support and treatment** for those rapidly approaching the end of their lives? This could also include question(s) about care and support for current or bereaved carers or families looking after someone at the end of their life.

Which of the following categories best describes you? (Please tick all that apply.)

We need your answer so we can fully process your questions. Your name or organisation will NOT be published in association with the question.

- | | |
|---|---|
| <input type="radio"/> I am in the last few years of my life | <input type="radio"/> I am a professional working with people in the last few years of life |
| <input type="radio"/> I am a carer or family member or partner or friend of someone in the last few years of their life | <input type="radio"/> I am a volunteer working with people in the last few years of life |
| <input type="radio"/> I am a bereaved carer or family member or friend | <input type="radio"/> I am a member of the public who has an interest in the subject |
| <input type="radio"/> Other, please specify _____ | |

Consent

By participating in this survey you are agreeing to allow us to anonymously publish your unanswered question(s) in an online tool for researchers called UK DUETs (UK Database of Uncertainties about the Effects of Treatments, library.nhs.uk/duets). UK DUETs also publishes research recommendations. This enables researchers to enhance existing research. Your name or organisation will not be published in association with your question(s).

By providing us with your unanswered question(s) you are consenting for us to enter them anonymously into SurveyMonkey for analysis. Data will be subject to SurveyMonkey's privacy policy which can be found online at surveymonkey.com/mp/policy/privacy-policy

If you do provide your personal contact details, we will keep them confidentially and securely, in accordance with the Data Protection Act.

Please note that there are rare circumstances under which the Palliative and end of life care Priority Setting Partnership will have a duty to share information provided in this survey with the relevant body, such as where abuse and/or criminal activity is disclosed, or where an individual is a risk to themselves or others (including children or vulnerable adults).

We are sorry, but we are unable to respond to specific personal questions that you may have about your own, or another person's care. If you need further support with any issues raised by filling out this survey this can be found at palliativecarepsp.org.uk

Need this in large print? Contact us at PeolcPSP@mariecurie.org.uk or call 020 7091 4153.
This survey is also available online at palliativecarepsp.org.uk

Survey - section 2:

Some questions about you

These questions will help us to understand the range of people who have responded to our survey.

1. Where do you live?

- England
- Scotland
- Wales
- Northern Ireland
- Republic of Ireland
- Other, please specify _____
- Prefer not to say

2. We would like to stay in touch with you so that we can keep you updated on the progress of the project and send you a report of the results in early 2015. Please tick below if you would like to be kept up to date:

- Yes please. I would like to be kept up to date on the progress of the project and the results.

Also, in autumn 2014 there may be an opportunity for you to get involved in workshops and focus groups to identify the most important questions we identify in the survey. Please tick below if you are interested in taking part in a focus group. We are happy to talk to you about your access needs if applicable.

- Yes please. I am interested in taking part in a focus group to prioritise the questions and would like to be invited.

If you answered '**Yes please**' to the previous question(s), please enter your contact details below. Your details will be treated with complete confidentiality.

Name: _____

Organisation (if applicable): _____

Address: _____

City/town: _____

Post code: _____

Country: _____

Email address: _____

Phone number: _____

(We will detach this section so we can keep your contact details confidentially)

section 2 continues overleaf

section 2 continued

Please tick how you would prefer us to contact you
(if you answered 'Yes please' to question 2):

- Email Phone Post

3. How did you complete this survey?

On your own

As part of a group (two or more people)

If you completed this as part of a group, how many were
in your group? _____

ONLY for health and social care professionals working in palliative care and/or with people at the end of life

4. Which is your primary profession *(please tick one box only)*

Palliative care doctor

Other specialist doctor, please specify

General Practitioner

Specialist palliative care nurse

Other specialist nurse, please specify

Nurse

Professional allied to medicine

Social worker

Care home, or home care, staff

Chaplain

Clinical researcher, please specify area of research

Other, please specify _____

Prefer not to say

Thank you for taking the time to complete this survey

Please return your completed survey by 30 April 2014 by email to
PeolcPSP@mariecurie.org.uk, or by freepost to:

FREEPOST RLUH-ATGY-BXSA

89 Albert Embankment
LONDON
SE1 7TP

If you need help with completing this form and/or if you would like to comment,
please either email us on the above email address or call on **020 7091 4153**.

You can help us by passing details of this survey on to anyone who might be interested.

You can tweet about us too **@PeolcPSP**.