

# End of life care

Single point of access survey – autumn 2014



## What is end of life care?

End of life care is about caring for people who have an advanced, progressive and incurable illness so they can live as well as possible until they die. It is about providing support that meets the needs of both the person who is dying and the people close to them.

## What are we planning to do?

In 2013 a survey was carried out to get the thoughts of patients, relatives, carers and staff about health and care services for people at the end of their life. The survey found that people struggled to get medical support in the evenings and at weekends, and that it can be difficult to know who to contact when extra support is needed.

We are looking at setting up a brand new free telephone service, exclusively for patients in the last years of life and their relatives / carers to use. The aim of the service would be to improve the care of patients and their relatives / carers and support people in their own home. The service would be available 24 hours per day, 7 days a week, 365 days per year. If a patient or their relative / carer has any concerns or questions about their condition they can call the telephone line at any time of the day or night. Our plan is that the service will be provided by experienced nurses who can give telephone advice, organise patients to be visited by healthcare professionals, arrange additional support for patients in their own home, and provide information about other services available.

## Why we need your views?

We want to know what you think about our plans for a 24/7 telephone service for people at the end of life and their carers. This will help us develop a service that meets the needs of local people.

**We value your views because they help us provide the services you need in the way you need them. Please take a couple of minutes to fill in this form and tell us what you think. You can also fill in this survey online here: [www.snapsurveys.com/wh/s.asp?k=140862713249](http://www.snapsurveys.com/wh/s.asp?k=140862713249)**  
**This survey is confidential and you don't need to fill in your name.**

Name:

Tel:

Email:

Address:

Postcode:

GP Practice:

If you are interested in finding out more about our work, please tick the box below and fill in your contact details.

**I would like to find out more about engagement work at NHS Leeds West CCG**

1. Are you completing this survey as:	A patient <input type="radio"/>	A relative / carer <input type="radio"/>		
2. The end of life care I/my relative receives is generally...	Excellent <input type="radio"/>	Good <input type="radio"/>	OK <input type="radio"/>	Poor <input type="radio"/>
3. Have you or your relative ever been involved with the palliative care team?	Yes <input type="radio"/>		No <input type="radio"/>	
4. Do you agree with the findings of the previous survey that there is a lack of medical support at evenings and weekends?	Yes <input type="radio"/>		No <input type="radio"/>	
5. Do you agree with the findings of the previous survey that it can be difficult for people at the end of their life and their carers to know who to contact for extra support if needed?	Yes <input type="radio"/>		No <input type="radio"/>	
6. If you or the person you care for were to become unwell outside of normal GP opening hours what would you do?	Call 999 <input type="radio"/>			
	Call 111 <input type="radio"/>			
	Call my GP surgery <input type="radio"/>			
	Ring district nurse <input type="radio"/>			
	Go to A&E <input type="radio"/>			
	Attend walk-in centre <input type="radio"/>			
	Wait until GP opens <input type="radio"/>			
	Call my existing out of hours support <input type="radio"/>			
Please tell us who this is: Other (please specify) <input type="radio"/>				
7. Do you think there is a need for a 24/7 telephone service exclusively for people in the last years of life?	Yes <input type="radio"/>		No <input type="radio"/>	
8. If you were to use the 24/7 telephone service, what would you like it to provide/ (tick all that apply)	Advice <input type="radio"/>			
	GP home visits <input type="radio"/>			
	Referral to social services <input type="radio"/>			
	district nurse home visits <input type="radio"/>			
	Organise equipment <input type="radio"/>			
	Other (please specify) <input type="radio"/>			
9. The nurse who answers the telephone would need to have access to the GPs medical records, would you be happy with that?	Yes <input type="radio"/>		No <input type="radio"/>	

<b>10. Are you aware of Carers Leeds and the support they offer</b>	Yes <input type="radio"/>	No <input type="radio"/>
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<b>11. To what extent do you agree with the following statements (this will help us understand what your care is like at the moment)</b>				
	Strongly disagree	Disagree	Agree	Strongly agree
<b>a. I was / am involved in decisions about my / my relative's care</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>b. I / my relative was / am treated with respect and dignity</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>c. My clinician explained my / my relative's treatment in a way I could understand</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>d. The people looking after me / my relative worked well together</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>e. I was / am given information to help me make future decisions about my / my relative's care</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>12. Please use the space below to share any thoughts you have about our proposal or how we can improve services for people at the end of their life.</b>

**We think that when patients and carers are involved in planning, developing and evaluating services, those services are more likely to meet the needs of local people.**

**If you would like to find out more about getting involved in designing the single point of access service, please tick this box  and make sure that you have filled in your contact details on the front of this form.**

<p>Please return this survey by <b>Monday 29 Sept 2014</b> to <b>Chris Bridle, FREEPOST RTEG-JRZR-CLZG, NHS Leeds West Clinical Commissioning Group, Suites 2-4, WIRA House, Ring Road, West Park, LEEDS LS16 6EB.</b> For more information call <b>(0113) 8435473.</b></p>
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Thank you for taking the time to fill in this survey. We will share the results of this engagement in the next few months. If you would like to know the outcome and how you have influenced the decision we make please ensure you have filled in your details on the front of this form. Alternatively you could visit our website for regular updates. [www.leedswestccg.nhs.uk/getting-involved](http://www.leedswestccg.nhs.uk/getting-involved)

## Equality Monitoring Form

My postcode is:	My GP surgery is:
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### What gender are you?

<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Prefer not to say
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### Transgender - is your gender identity different to the sex you were assumed to be at birth?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Prefer not to say
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### Pregnancy and Maternity

<input type="checkbox"/> I am pregnant	<input type="checkbox"/> I have given birth within the last 26 weeks
<input type="checkbox"/> Not applicable	<input type="checkbox"/> Prefer not to say

### What is your age?

<input type="checkbox"/> Under 16	<input type="checkbox"/> 16 - 25	<input type="checkbox"/> 26 - 35
<input type="checkbox"/> 36 - 45	<input type="checkbox"/> 46 - 55	<input type="checkbox"/> 56 - 65
<input type="checkbox"/> 66 - 75	<input type="checkbox"/> 76 - 85	<input type="checkbox"/> 86 +
<input type="checkbox"/> Prefer not to say		

### What is your sexual orientation?

<input type="checkbox"/> Bisexual (both sexes)	<input type="checkbox"/> Heterosexual/straight (opposite sex)	<input type="checkbox"/> Lesbian/gay woman (same sex)
<input type="checkbox"/> Gay man (same sex)	<input type="checkbox"/> Prefer not to say	

### Do you consider yourself to belong to any religion?

<input type="checkbox"/> Buddhism	<input type="checkbox"/> Christianity	<input type="checkbox"/> Hinduism
<input type="checkbox"/> Islam	<input type="checkbox"/> Judaism	<input type="checkbox"/> Sikhism
<input type="checkbox"/> No religion	<input type="checkbox"/> Prefer not to say	
Other (please state)		

### What is your ethnic background?

Asian, or Asian British	Black, or Black British	Mixed/ multiple Ethnic groups	White	Other
<input type="checkbox"/> Chinese	<input type="checkbox"/> African	<input type="checkbox"/> Asian & White	<input type="checkbox"/> British	<input type="checkbox"/> Arab
<input type="checkbox"/> Indian	<input type="checkbox"/> Caribbean	<input type="checkbox"/> Black African & White	<input type="checkbox"/> Gypsy/Traveller	<input type="checkbox"/> Other
<input type="checkbox"/> Pakistani	<input type="checkbox"/> Other	<input type="checkbox"/> Black Caribbean & White	<input type="checkbox"/> Irish	
<input type="checkbox"/> Other		<input type="checkbox"/> Other	<input type="checkbox"/> Other	
If any other ethnic background, please state here:			<input type="checkbox"/> Prefer not to say	

### Do you consider yourself to have a disability? Please tick all that apply

Under the Equality Act 2010 a disability is defined as 'a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'.

<input type="checkbox"/> Long-standing illness or health condition e.g. cancer, diabetes, HIV, etc		
<input type="checkbox"/> Learning disability/difficulty	<input type="checkbox"/> Mental Health condition	<input type="checkbox"/> Physical or mobility
<input type="checkbox"/> Hearing	<input type="checkbox"/> Visual	<input type="checkbox"/> Other (please state)
<input type="checkbox"/> Prefer not to say		

### Do you look after, or give any help or support to a family member, friend or neighbour because of long term physical disability, mental ill-health or problems related to old age?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Prefer not to say
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