

Action Sheet 1

End of life care champions

You are:

Someone who wants to act as a local champion for palliative and end of life care. You might:

- ➔ Be living with a progressive and/or incurable condition(s) and/or approaching the end of life
- ➔ Be caring for someone who fits the above description, or have done so in the past
- ➔ Have professional experience of palliative and end of life care, or a passion for this area.

You want:

To know how to access and improve high-quality palliative and end of life care in the new system.

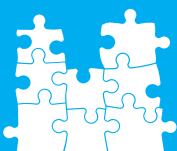
You can start by:

1. Being clear about what is needed: What do you or the person approaching the end of life need to feel better supported and/or cared for? What should be prioritised?

- TIP:** The government records end of life care experiences through the national survey of bereaved people (VOICES). You can find out what carers are saying about services in your area and use it in your influencing by visiting www.dh.gov.uk/health/2012/07/voices
- TIP:** Look at the five priority outcomes included in this toolkit (see Introduction booklet) or the resources produced by the Dying Matters coalition - www.dyingmatters.org

2. Finding out what's available:

- Ask your GP or practice nurse what support is available.
 - TIP:** Be aware that your practice might not be familiar with all the services available locally. If they don't know, ask them to let you know who to contact for further information.
- Find out if you have a hospice or palliative care team nearby and what they provide.
 - TIP:** Search by your postcode at www.helpthehospices.org.uk or by calling 020 7520 8200
- Talk to any other professionals you are in touch with - your social worker, or, if you have one, your condition-specific nurse or doctor. Ask them what they think is good, and what's missing.



3. Knowing your rights: Familiarise yourself with -

- a. [The NHS Constitution](http://www.nhs.uk/choiceinthenhs) - sets out the care you should expect from the health system
www.nhs.uk/choiceinthenhs
- b. [The NICE End of Life Care Quality Standard](http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp) - sets out 16 things you should expect in the last 12 months
www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp

TIP: Professionals might not be familiar with these documents so you may wish to share a copy with them.

4. Improving what's available: If the services laid out in a) & b) aren't available locally, find out if they existed before the new structures came into place.

- a. [Contact the General Practice Patient Participation Group \(PPG\)](#) - every practice has one.

TIP: Ask for end of life care to be an item on the agenda.

TIP: The people who run the practice might be involved in the local Clinical Commissioning Group (CCG) who make decisions. Give them a copy of the CCG Action Sheet.

- b. [Contact your local MP](#) who can help to raise the profile of your situation and put pressure on local and national decision-makers to improve the situation (it's their job!)

TIP: Find out who your MP is here: findyourmp.parliament.uk

5. Reporting back: Tell us what was good, and not so good, about services locally, and what you did to try to change things: ncpc.nativeeye.com/toolkit

We can't get involved in individual situations or complaints but we do want to hear experiences.

6. Going further: Consider getting in touch with your local HealthWatch, which may previously have been called a Local Improvement Network (LINK). See the Action Sheet on local HealthWatch in this toolkit.

The NHS Constitution states that 'The NHS belongs to the people. It is there to improve our health and well-being, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives.' The Health & Social Care Act requires CCGs to secure services which promote the Constitution.

Useful resources:

➔ For practical help to talk about dying, death and bereavement visit the Dying Matters coalition website - www.dyingmatters.org

➔ For facts, analysis and campaigning, and help involving people approaching the end of life and their carers, visit NCPC's website - www.ncpc.org.uk

