People who are experiencing a life-limiting condition or nearing the end of life and those who care for them, or have done so in the past, have a real insight into why and how to talk about issues around dying and death. They can act as ‘Dying Matters Champions’.

**People with personal experience bring:**
- Inspiration – powerful, personal reasons why we need to be more open
- Practical skills – Insights into how to open up conversations and an understanding of how it feels

**How are they currently engaged with the public on this issue?**
- Speaking on local and national media
- Speaking at conferences
- Helping produce and shape materials to prompt and assist conversations
- Speaking to local community groups and getting them involved
- Planning Dying Matters week activities
- Using Dying Matters materials to support others in having conversations

**What approaches and activities would interest them and what would not (dos & don’ts)?**
Opportunities to engage and involve people with personal experience are limitless, providing you’re flexible.

**Some tips:**
- Don’t make assumptions: it’s easy to assume that people are ‘too ill’ to be involved or that it’s ‘too soon’ for others. Just ask people what they’d like to be involved in, and how, and make every effort to make this possible.
- Support people when they’re involved. e.g.
  - Transport
  - Expenses
  - Making sure they are clearly briefed
  - Checking in afterwards to make sure they’re ok
  - Feeding back about the impact of involvement
  - Making sure they’re clear that they can stop at any point
  - Out of courtesy, checking with people each time you would like to use their story
  - If a story will appear in the media, letting the people involved know when it will be broadcast
- Do everything you can to make their involvement interesting and enjoyable

Following their son’s death, Dorothy and Tony have campaigned for better end of life care.

For many people, encouraging and supporting others to talk more openly can be a way of leaving a legacy and making life better for others.
Dorothy and Tony Bonser

Dorothy and Tony live between Preston and Blackburn. Their son, Neil, died of cancer in 2009. Having spent most of their lives as teachers, they now work as volunteers for Dying Matters and for their local hospice. They are both driven by the desire to make a difference for others in the level and nature of support given to those nearing the end of their lives, their families and carers.

**Their activities include:**
- Local and national media
- Speaking at conferences locally and nationally
- Involved in producing and reviewing Dying Matters materials and leaflets
- Speaking to Rotary, Women’s Institute, schools and youth organisations
- Networking with End of Life Care and Cancer Networks in the North West
- Working with Lancaster University End of Life Care Peer Education project
- Working with the University of Central Lancashire End of Life Project
- Volunteers at their local hospice
- Providing practical help for local people who are in the final stages of life and their loved ones

**The difference it makes to Dying Matters**
Tony and Dorothy’s experience is a really powerful example of how important it is to be open about issues around dying and death. They not only help people to see why they should try to open these conversations, but how.

**The difference it makes to them**
The only way they can make any sense of the death of their son Neil, aged 35, is to try to make things better for others. Being able to articulate their experiences and hopes as ‘lay’ people can have a very positive influence on end of life care for others.

Mandy Paine

Mandy is 49 and has Chronic obstructive pulmonary disease, a life-limiting respiratory condition. She always tries to turn negatives into positives. She has ‘put her house in order’ by planning her funeral including writing her own eulogy and writing and recording her own music.

**Her activities include:**
- National media – Radio 4, Channel 4, BBC television, The Times newspaper, Community Care
- Local media
- Taking Dying Matters information everywhere she goes, and speaking about it with people in her local community e.g. Tescos, charity shops, church, funeral director and nursing homes
- Involved in producing and reviewing Dying Matters leaflets and materials

**Useful weblinks:**
www.involve.org.uk
www.user-involvement.org.uk
www.ncpc.org.uk

By Jo Black, Involvement Manager, the National Council for Palliative Care
and
Dorothy Bonser, Tony Bonser and Mandy Paine, Dying Matters Champions